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COMMUNICATION SKILLS, KNOWLEDGE AND VIEWS OF HEALTHCARE PROFESSIONALS PROVIDING SUPPORTIVE CARE WHEN A PARENT HAS CANCER

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“But just think, there are simply no experiences that can compare to those we have in childhood. Imagine if people could understand how important everything related to children is - their books, their movies, their music, everything, everything. Because it shapes them for their entire lives.”

Astrid Lindgren

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1. BACKGROUND

1.1. Cancer and its psychological impact

In Germany, approximately 500,000 new patients receive a cancer diagnosis per year and 4.5 million people living in Germany have received a cancer diagnosis in the last 25 years [1]. A cancer diagnosis and its treatment can profoundly impact the lives of patients, relatives and friends in many ways. Receiving a cancer diagnosis - a life-threatening illness - induces significant psychological distress in one in two patients [2]. Further, having cancer can impose cancer-related fatigue [3], pain [4] and a variety of functional impairments [5, 6], negatively affecting their quality of life. Due to advancements in treatment options and higher survival rates in recent years, an increasing number of people live with and beyond cancer. The effects of the disease and its treatment continuously affect their lives. In addition to the physical side effects of cancer and its treatment, including pain, fatigue, sleep problems, and tissue damage, many cancer patients experience psychological distress and limitations in their social functioning [7]. These effects can influence aspects of self-concept, body image, and role fulfillment within family, occupational, and leisure contexts. Psychologically, various stressors and themes emerge at different stages of the illness and treatment trajectory. The most prevalent psychological comorbidities observed in this population include anxiety, depression, and adjustment disorders. Emotional distress, which is an integral aspect of the psychological adaptation process when coping with a cancer diagnosis as a significant life stressor, may require clinical intervention and personalized support when experienced at elevated levels [8-11].

Psycho-oncological support services play a crucial role in modern, patient-centered cancer care by addressing the emotional, psychological, and social needs of both patients and their families [12] as they can significantly improve quality of life and overall well-being of cancer patients [13, 14]. In Germany, the National Cancer Plan as well as the S3 Guideline on psycho-oncology emphasize the importance of providing appropriate psycho-oncological care to all cancer patients and their relatives when needed [12]. This includes the early identification of psycho-oncological or psychosocial support needs and treatable mental disorders in patients and their families, as well as ensuring that such care is available across inpatient, outpatient, and rehabilitative settings [12].

However, not every cancer patient requires specialized psycho-oncological support. For patients without clinically significant distress, adequate support from their direct medical providers is usually sufficient. To provide adequate care for patients and guide them toward additional support, a foundational qualification in psychosocial issues is essential for all professional groups working in oncology. The goal is to address the distress of those affected in a timely manner and to refer them

to specialized personnel when needed. By routinely assessing and addressing psychosocial distress in all settings [2], healthcare professionals (HCPs) can better guide patients and their families to appropriate specialized support services, thereby improving overall quality of life and well-being and providing personalized, patient- and family-centered cancer care [15-17].

1.2. When a parent has cancer – Challenges, burden, and impact on family dynamics

Approximately 14%-25% of parents with dependent children are diagnosed with cancer [18]. Among women, breast cancer is the most common cancer worldwide [19], with up to 10% of diagnosed patients being under the age of 40 [20], a demographic that is typically of childbearing age and often responsible for parenting minor children. However, assessment of parental status does not take place routinely [21].

The prevalence of cancer patients who are parents of minor children underscores significant implications for family life. A cancer diagnosis can have a major impact on the entire family as the disease and its treatment can influence family routines, relationships, parental roles and responsibilities, as well as financial stability [22-25].

Parents diagnosed with cancer who are raising minor children often experience significantly higher levels of stress and anxiety than those without such responsibilities [26, 27]. The systematic review by Johannsen et al. [28] indicates that between 7% and 83% of parents with cancer show signs of probable clinical depression, while 19% to 88% meet criteria suggesting probable anxiety disorders. These findings are in line with other studies about parents with serious illnesses, where patients, who are seriously ill and have parental responsibilities, experience significantly heightened levels of psychosocial distress, major depressive disorder, and generalized anxiety compared to their peers [29, 30]. The burden of managing a life-threatening illness and enduring often intensive treatments is complemented by parental concerns related to maintaining stability and continuity in their children's lives. Cancer patients parenting minor children frequently struggle with how to fulfill and uphold their responsibilities as reliable and caring caregivers, balancing the demands of treatment with the emotional and practical needs of their children [31-33]. The worry about meeting the expectations of being a ‘good’ parent, providing emotional support, and ensuring their children’s well-being further intensifies their psychological burden [34, 35]. Dencker et al. [36] conducted a qualitative study revealing that parents with cancer faced significant challenges in navigating their roles as parents while managing serious illness. Many struggled to maintain their parental identity and, in some cases, chose to separate this identity from their patient role [36]. This separation was often driven by a focus on survival and the desire to shield their children from the emotional and physical toll of acute treatment, ensuring that the children would not witness their parent in a

vulnerable state [36]. Additionally, Moore et al. [37] found that parents' sense of self-efficacy declined following a cancer diagnosis, with many expressing uncertainty about their ability to adequately meet their children's needs. Cancer patients who are also parents of minor children frequently experience concerns about their children's well-being, underscoring the emotional and psychological burden they face while managing their illness. Examples of these worries from parents with cancer have been synthesized by Li et al. [32] and include themes like *"cancer may be passed on to the children"*, *"a parent's cancer diagnosis can rob a child of a happy childhood"*, *"decreased participation of children in recreational and social activities"* and *"Parents rush to teach their children life skills"*.

This unique "double burden" - being a parent and a patient - can influence cancer patients' medical decision-making [38]. Parents with advanced cancer often balance the competing priorities of quality and quantity of life, frequently choosing more aggressive treatments to extend their lives and maximize time with their children, while also weighing the side effects that could impact their ability to fulfill parenting responsibilities [30, 39]. Additionally, they are less likely to engage in advance care planning, such as drafting "do-not-resuscitate" (DNR) orders or creating a healthcare directive [27, 30]. Being a parent with cancer also affects treatment adherence. Childcare, for example, is a key factor in timely care. Li et al. found that 40% of cancer parents undergoing radiation therapy had to reschedule and 14% missed at least one appointment due to childcare conflicts, with over 75% reporting that childcare support would have improved adherence to the planned regimen [40].

Children of parents with cancer experience significant disruptions in their family routines, leading to increased psychosocial stress and vulnerability [41, 42]. These children often face emotional burdens that can deeply affect their well-being, with studies showing that they are approximately twice as likely to develop psychological symptoms compared to their peers [43]. Children and adolescents whose parents had cancer experienced higher levels of anxiety, depression, and decreased self-esteem compared to their unaffected peers. They also reported greater psychosocial difficulties, including internalizing issues, psychological distress, post-traumatic stress disorder symptoms, and increased school absenteeism [44-46]. Even without direct knowledge of the illness, children often sense that something is wrong, leading to heightened stress and anxiety [47]. Therefore, providing age-appropriate information and ensuring timely communication about a parent's cancer diagnosis can significantly reduce the risk of negative psychological and physical consequences for affected children [42, 48]. Clear communication helps children understand the situation in a way that is manageable for their developmental level, which can alleviate confusion and fear. Parents often act as the primary gatekeepers to their children's emotional support, with

many being the key informants about their children's needs [18]. As the primary caregivers, parents are pivotal in ensuring that their children receive appropriate psychosocial support. While the burden on children is evident, parents also observe potential positive changes in their children, similar to the concept of post-traumatic growth identified in adult cancer patients [18, 49]. This highlights the multifaceted impact that a parent's cancer diagnosis can have, where, despite challenges, there may also be opportunities for emotional development and resilience in children. Children of parents with cancer do not necessarily experience an increased psychological burden [50], as many are able to adapt effectively to the new circumstances**.** They can also play and be happy during such difficult times, leading adults to sometimes perceive that the parent's illness has no impact on the child. However, even these children experience fear and worry during the phase of a parental cancer disease. To help them cope with this burden as effectively as possible, they need extra attention and care. Children have a unique sensitivity, a heightened awareness of moods and notice when their parents' mood or behavior changes [47], which they often are not able to understand. Various associated risks as well as protective factors significantly influence the coping of a child whose parent has cancer or a life-limiting disease. Positive family functioning, including family cohesion and affective responsiveness within family relationships, as well as the psychosocial well-being of the ill parent are associated with lower psychological symptoms in children of parents with cancer [51, 52]. Parental depression, especially in mothers, dysfunctional family relationships, as well as medical variables such as recurrent illness, metastasized cancer, or poorer prognosis significantly increase the risk of psychological symptoms in children [51, 53-56]. These findings highlight the urgent need for targeted support and increased awareness to support the emotional and behavioral well-being of children affected by a parent's cancer diagnosis. Providing such support within a family-centered approach is essential and aligns with the goal of family-supportive services that help families navigate the challenges of cancer together.

Specific psychosocial, family-oriented interventions can help parents to foster open communication about cancer within the family and provide age-appropriate information to their children [57]. They also offer emotional support and strengthen parents' confidence in their parenting abilities [58]. For children of cancer patients, interventions offer guidance on coping with their parent's illness, often through supportive groups that provide opportunities to share experiences, reduce feelings of isolation, and adopt positive coping strategies [25, 59-61], while some programs specifically focus on enhancing their psychological well-being through psychoeducation, social connection, and the development of coping mechanisms [62]. In a 2016 review, Inhestern et al. found that the evaluation of family interventions observed positive outcomes, including improvements in parents'

and children's quality of life, reductions in depression scores and psychiatric symptoms in parents, and enhancements in family communication and functioning [57].

1.3. How should I tell them? – Communication within the family about having cancer

Communicating with children about a parent's cancer diagnosis is a critical yet challenging aspect of family life. Parents often face significant uncertainty and emotional challenges when navigating this sensitive topic, worrying about how to convey information that supports their children without causing unnecessary distress. Many parents express a lack of confidence in addressing their children's emotional needs, which can contribute to insecurity about their parenting abilities [32, 34, 63-66]. Research consistently highlights that effective communication is central to maintaining family resilience and promoting psychological well-being in children when a parent is facing a life-threatening illness [35, 41].

One of the most significant challenges for parents with cancer is deciding if, when, and how to discuss their illness with their children. Parents fear that sharing too much or too little information may have adverse effects on their children's emotional well-being [67]. This uncertainty is particularly acute at the beginning of treatment, when parents often feel overwhelmed by their own diagnosis and treatment planning process [36]. The emotional burden of coping with cancer while parenting increases stress levels, and some parents prefer to shield their children from their pain, aiming to "maintain a fatherly image" or preserve normal family interactions [32]. However, the physical and psychological changes associated with cancer hinder their ability to communicate effectively with their children. Not knowing how to address their children's concerns can make parents feel inadequate, compounding their own fears and anxieties [67]. This sense of helplessness is often exacerbated by the belief that they are failing their children if they cannot shield them from distress [68].

Research consistently underscores the importance of open, age-appropriate communication between parents and children [42, 48, 64, 66, 69] as it can impact children's well-being and their ability to adapt to the challenges of the parent's illness [56]. Studies suggest that communication is most effective when delivered incrementally, in small, manageable pieces, with more detailed information provided as the illness progresses [41]. Yet, many parents mistakenly believe their children, especially younger ones, are too young to comprehend the implications of cancer. This assumption often leads to withholding information, even though evidence shows that children as young as three can perceive changes within the family and benefit from age-appropriate discussions [41].

Parents frequently report feeling ill-equipped to manage conversations about their illness, citing uncertainty about how to initiate the dialogue or address their children's emotions [67]. Hammersen et al. [70] found that more than two-thirds of parents desired information on supporting their children, yet only a small fraction received family-specific psychosocial support. Similarly, Ernst et al. [71] observed that while 73% of parents expressed a need for psychosocial assistance, only 9% used such resources, highlighting significant gaps in care delivery.

Historically, cancer care has prioritized the patient's needs, sometimes neglecting the well-being of other family members. However, a more holistic, family-centric approach recognizes the importance of including children as essential participants in the caregiving dynamic [72]. Adopting this broader perspective acknowledges that effective family communication is not only central to the well-being of the patient but also critical for the emotional health and resilience of children and other family members.

As parents are often the primary source of information for their children, it is crucial to proactively address the unique needs and challenges of parents with cancer as part of preventive psychosocial family support in cancer care [63, 73].

1.4. The role of healthcare professionals when a parent has cancer

In Germany, cancer care guidelines emphasize the importance of HCPs incorporating patients' mental and social well-being into medical conversations and involving their relatives, including children, in the care process [12, 74]. Additionally, certification criteria are guided and informed by these guidelines [75].

In order to incorporate patient's perspectives and to address the psychological and interpersonal impacts of cancer treatment, various (public) healthcare organizations, such as the WHO [76, 77] as well as strategic initiatives like the National Cancer Plan in Germany (German: Nationaler Krebsplan, NKP), advocate for the promotion of patient-centered care [78]. While the concept of patient-centered care is widely recognized in healthcare research and implementation, its definition varies across contexts, leading to ambiguity due to inconsistent terminology and references [79, 80]. Approaches such as patient-centered, person-centered, relationship-centered, family-centered, and individualized care all emphasize the involvement of the patient and the family [81]. Together, these concepts foster active partnerships "*among practitioners, patients, and their family, ensuring that decisions respect patients' wants, needs, and preferences, and that patients have the education and support they need to make decisions and participate in their own care, as well as participate in quality improvement efforts"* [82], moving away from traditional models that regard patients as passive recipients of care [83, 84].

Patient-centered communication, as a fundamental element of patient-centered care, serves as a vital communication process between HCPs, patients, and their family members, emphasizing the patient's needs, preferences, and values while playing a crucial role in the integrated model of patient-centeredness, particularly in the clinician-patient encounter [80, 85].

Communication is a fundamental aspect of healthcare delivery, serving as both an interactional process and a core clinical skill. Gilligan et al. summarized this dual role in their Ottawa Consensus Statement, defining communication in healthcare as *"the interaction and exchange of (verbal and non-verbal) information that takes place within a collaborative relationship within a healthcare context"* [86]. This definition highlights communication as a dynamic process that underpins effective collaboration between HCPs, patients, and family members. Communication has long been recognized as one of the central 'tools' of healing available to HCPs [87]. Its goal-oriented nature within healthcare encounters - whether addressing patient needs or collaborating with colleagues - requires a high level of skills to navigate diverse communication styles and adapt to varying contexts [86, 87]. For HCPs, this means being equipped with communication skills to engage effectively in a wide range of situations, from delivering difficult diagnoses to facilitating shared decision-making or addressing family concerns.

Within the framework of patient-centered care, clinician-patient communication is influenced and is shaped by other patient-centered principles - such as viewing the patient as a unique individual - and activities, such as the type of information shared, the inclusion of family members in care decisions, and the coordination of medical and non-medical care.

By integrating both verbal and non-verbal communication skills, patient-centered communication directly and indirectly enhances patient understanding, treatment adherence, motivation, trust, as well as overall health and well-being including patient satisfaction and perceptions of service quality [88-90]. Furthermore, it strengthens the relationship between patients and HCPs [81], can improve HCPs' job satisfaction and stress experience [81, 91] and ensures patient safety [92].

Thus, effective communication in healthcare is more than a technical skill. It is a relational process that enables HCPs to translate patient-centered care principles into meaningful patient and family interactions, ultimately enhancing care quality and outcomes (see Figure 1).

In order to provide patient-centered care to families with parental cancer, it is essential that all HCPs working in oncology are equipped with the necessary knowledge, communication skills and self-efficacy [93]. Understanding a patient's family status is essential for HCPs to proactively address child- and family-specific aspects.

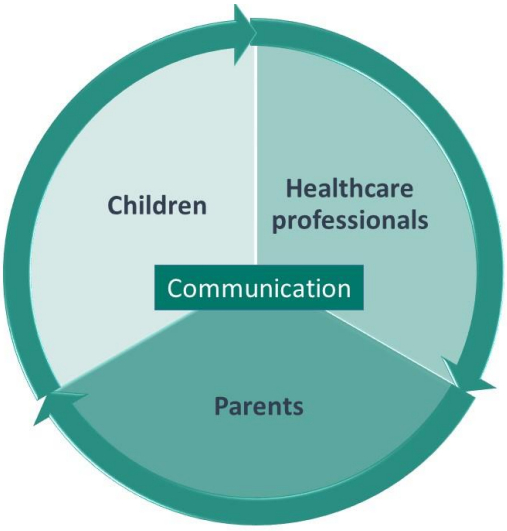

Figure 1. Complex inter-relationship of communication between parents who have a life-limiting illness, their children and professionals [41]

HCPs play a crucial role in identifying cancer patients who are parenting minor children, assessing their specific needs, and facilitating access to psychosocial care when required [34, 36, 63, 65]. Research shows that parents with cancer seek guidance from HCPs on communicating with their children [65, 94-96] as well as wish to receive specific information for example on how their children can manage to cope, about assistance with practical matters, or about psychosocial support services [71, 72, 96]. Tailored interventions, such as information booklets, can support parents to have age-appropriate conversations with their children, thus reducing parental stress and enhancing family communication [34, 41, 97, 98]. Effective family communication is associated with better relationship functioning and adjustment to a cancer diagnosis within the family, highlighting the importance of HCPs supporting open communication within the family [99]. By equipping parents with the tools and confidence to navigate these conversations, HCPs can enhance patient-centered care. Information tailored to individual needs is closely linked to patient satisfaction and quality of life [100].

However, family-focused recommendations by HCPs, which are also empirically based, are largely lacking [34, 35, 97, 101]. Additionally, Schouten et al. found out, that less than 50% of HCPs routinely discuss child- and family-specific themes with patients [102]. This is supported by a recent interview study by Johannsen et al. [96], reporting that many of the interviewed cancer patients with minor children were not routinely asked about their parental status, and parental concerns often emerged coincidentally rather than proactively. Additionally, the study highlighted mixed experiences with empathic communication of the HCPs: while some patients described attentive

and natural discussions of parental concerns, others reported a lack of sensitivity from their HCPs on child- and family-related aspects, including issues like fertility and family planning [96].

Overall, various studies indicate that cancer patients parenting minor children feel that HCPs often overlook inquiries about their children, causing reluctance to discuss the topic and leaving them feeling alone in facing family-related difficulties [96, 103, 104]. Reported HCPs barriers include limited training, insufficient competencies, time constraints, and structural challenges [34, 63, 71, 94]. Previous studies found that HCPs often feel inadequately prepared to communicate about these aspects or to offer psychosocial support to patients with minor children [63, 105]. Also, HCPs seem to be unaware about their responsibility to communicate about these psychosocial topics [96]. However, few studies assessing the views of HCPs are available [63, 106], most focusing on end-of-life conversations [94, 107, 108] or the perspective of cancer patients when communicating with HCPs about child- and family-related aspects [36, 96].

To overcome these limitations, educational interventions designed to enhance HCPs knowledge and communication skills in addressing family-specific aspects are one approach in healthcare research [48, 65, 109]. For example, communication skills trainings (CSTs) have shown to increase HCPs' empathy, knowledge, or self-efficacy, leading to improved patient-reported outcomes, such as increased satisfaction [110, 111]. Integrating such trainings and educating HCPs “to be adaptive, sensitive and reflective in their communication” [86] could support cancer patients and their families, aligning with patient-centered care principles.

Despite strong advocacy for patient-centered care in oncology by the National Cancer Plan since 2008 and an emphasis to also include children as relatives - as outlined in German cancer guidelines [12, 74, 78], the provision of comprehensive support to families affected by parental cancer remains insufficient.

While there is a significant demand from patients for relevant information regarding parental cancer [65, 71, 72, 94-96], HCPs often face barriers that hinder effective communication and support. These include insufficient routine discussions about family-specific aspects [96, 102], limited training, emotional challenges, and time constraints [34, 63, 71, 94, 112], all of which limit HCPs' ability to fulfill their roles in supporting affected families.

2. RESEARCH GAPS, AIMS AND QUESTIONS

The preceding sections outline the substantial psychological impact of cancer on patients, particularly those who are parents of minor children, and emphasize the critical role of HCPs in addressing these specific challenges.

While existing literature highlights the burdens faced by parents with cancer, including heightened distress and anxiety, there remains a notable gap regarding how HCPs communicate with these parents during such critical times [34, 35, 96, 97, 101, 102]. Despite strong advocacy for patient-centered care in oncology, as outlined in German cancer guidelines and reinforced by the National Cancer Plan since 2008 to also include children as relatives [12, 74, 78], the provision of comprehensive support to families affected by parental cancer remains insufficient. While there is a significant demand from patients for relevant information regarding parental cancer [65, 71, 72, 94-96], HCPs often face barriers that hinder effective communication and support. These include insufficient routine discussions about family-specific aspects [96, 102], limited training, emotional challenges, and time constraints [34, 63, 71, 94, 112], all of which limit HCPs' ability to fulfill their roles in supporting affected families.

While various reviews indicate that CSTs in oncology can enhance HCPs' communication abilities [111, 113-115], the overall quality of existing programs tends to be moderate, and instruments measuring patient-centered communication are too heterogeneous, not validated [114], or not comprehensive [116]. Especially for the German context, current patient-centered assessments are lacking [117, 118]. Additionally, it remains unclear whether and to what extent parental themes are incorporated within these CST programs.

To ensure adequate care for cancer parents and their families, including identification and addressing specific needs as well as referral to specialized support services when needed, it is essential to raise awareness among HCPs regarding child- and parent-related aspects and to strengthen and expand HCPs competencies in this area [94, 105].

According to the Medical Research Council (MRC) framework for developing and evaluating complex interventions [119], the development phase of an intervention must address core elements such as the intervention’s context, its stakeholders, and the identification of key uncertainties. Particularly, qualitative evaluations offer valuable insights into the challenges and enablers associated with implementing the acquired skills [120, 121]. Therefore, this dissertation was informed by using a mixed-methods approach [122] and applying the MRC framework [119] for developing and evaluating complex interventions (see section 5, Figure 4), with its four phases:

1. Development: Identifying evidence, theory, and key components of the intervention.
2. Feasibility: (Pilot-)Testing whether the intervention is acceptable and feasible.
3. Evaluation: Assessing effectiveness, cost-effectiveness, and the mechanism of impact.
4. Implementation: Supporting uptake, adaptation and sustainability in the real-world setting.

Building on the existing evidence that has identified several research gaps, this dissertation explores and analyzes the communication of HCPs when a parent has cancer through four distinct studies and their individual aims and research questions:

Study 1:

Aim: To systematically identify evaluated communication training programs for HCPs working in oncology, which incorporate the topic of "cancer and parenthood" through a comprehensive literature review.

Research questions:

1.1. What scientifically evaluated interventions (e.g., communication training programs) are available for HCPs that include specific modules addressing child- and family-related aspects when a parent is diagnosed with cancer?

1.2. How effective are these interventions?

Related publication | Publication 2:

Frerichs W, Geertz W, Johannsen LM, Inhestern L & Bergelt C. (2022). *Child- and family-specific communication skills trainings for healthcare professionals caring for families with parental cancer: A systematic review.* PLoS One, 17(11): e0277225. doi: 10.1371/journal.pone.0277225.

Study 2:

Aim: To explore HCPs' experiences when communication about child- and family-related aspects in cancer care and their opinions about the importance of including these aspects in cancer care.

Research questions:

2.1. What are HCPs' experiences when communicating about child- and family-related aspects in cancer care when a parent has cancer?

2.2. What attitudes do HCPs' have about the importance of including child- and family-related aspects in cancer care?

Related publication | Publication 4:

Frerichs W, Johannsen LM, Inhestern L & Bergelt C. (2025). *Providing care to cancer patients parenting minor children: A qualitative study on healthcare professionals' communication practice.* Patient Educ Couns Jan 13;133:108666. doi: 10.1016/j.pec.2025.108666.

Study 3:

Aim: To evaluate the feasibility and effectiveness of a newly developed training program for HCPs in oncology to enhance their competencies in caring for cancer patients parenting minor children using a three-armed randomized controlled pilot-trial (RCT) comparing a face-to-face-training with an e-learning and waitlist-control group.

Research questions:

3.1. What is the feasibility of the two training formats (face-to-face and e-learning) and the evaluation concept in the context of a training program on cancer and parenthood?

3.2. What is the preliminary effectiveness of the training program on cancer and parenthood in relation to primary and secondary outcomes?

Related publications | Publication 1:

Inhestern L, **Frerichs W**, Johannsen LM, Bergelt C. (2019). *Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot-study.* BMJ Open, 9(10):e032778. doi: 10.1136/bmjopen-2019-032778.

Publication 3:

Johannsen LM*, **Frerichs W*,** Philipp R, Inhestern L, Bergelt C. (2023) *Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study.* Psychooncology. 32(10):1567-1577. doi: 10.1002/pon.6207.

*****shared first authorship

Study 4:

Aim: To develop and assess the psychometric properties of a questionnaire that can measure the self-efficacy of HCPs in their communication competencies, which can be applied in a pilot-RCT evaluating a newly developed CST focusing on communication in the context of parental cancer.

Research questions:

4.1. What is the face and content validity of the translated German version of the Self-Efficacy Questionnaire (SE-12-G)?

4.2. What are the psychometric properties of the German version of the Self-Efficacy Questionnaire (SE-12-G) by performing a secondary analysis of data from a pilot-RCT?

Related publication | Publication 5:

Frerichs W, Johannsen LM, Inhestern L & Bergelt C. *The German version of the self-efficacy questionnaire (SE-12-G) in a sample of healthcare professionals: Translation and psychometric properties*, 16 September 2024, SUBMITTED to BMC Medical Education: PREPRINT (Version 1) available at Research Square [https://doi.org/10.21203/rs.3.rs-4836626/v1].

3. METHODS

The underlying dissertation was conducted within the study “Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study” (German: Enwicklung eines Training für Behandelnde von Krebspatient:innen zur Stärkung der Kompetenz im Umgang mit krebskranken Eltern minderjähriger Kinder; Acronym: KOMKEK study) [73, 123], funded by the innovations fund of the Federal Joint Committee in Germany (grant number 01VSF17052). The methods employed in the KOMKEK study are outlined below, followed by a summary of additional methods to address the research aims and questions of this dissertation. For comprehensive details regarding these methods, please refer to the attached full-text publications in section 11.

3.1. Overview of the KOMKEK study

The KOMKEK study started in July 2018 and finished in December 2021. The study was carried out in accordance to the Helsinki Declaration of the World Medical Association and principles of good scientific practice and was registered within the German Clinical Trial Register (DRKS-00015794). Additionally, ethical approval was granted by the Local Psychological Ethics Committee of the Center for Psychosocial Medicine, UKE, Germany (LPEK-001).

3.1.1. Objectives, study design and methods of the KOMKEK study

The study, using a mixed-methods intervention research design [122], aimed to enhance the communication competencies of HCPs regarding child- and family-oriented aspects of cancer care. It was designed as a Phase I and Phase II study [124] and consisted of two distinct phases (see Figure 2), encompassing two main objectives:

(1) to develop a training program focusing on "cancer and parenthood" for HCPs in oncology—including doctors, nursing staff, social workers, and psychologists—and
(2) to conduct a pilot evaluation study of this newly developed training program for various HCPs working with cancer patients within a pilot-RCT.

A study protocol was published (Publication 1) outlining the objectives, design, methodology, and analysis plan of a research project.

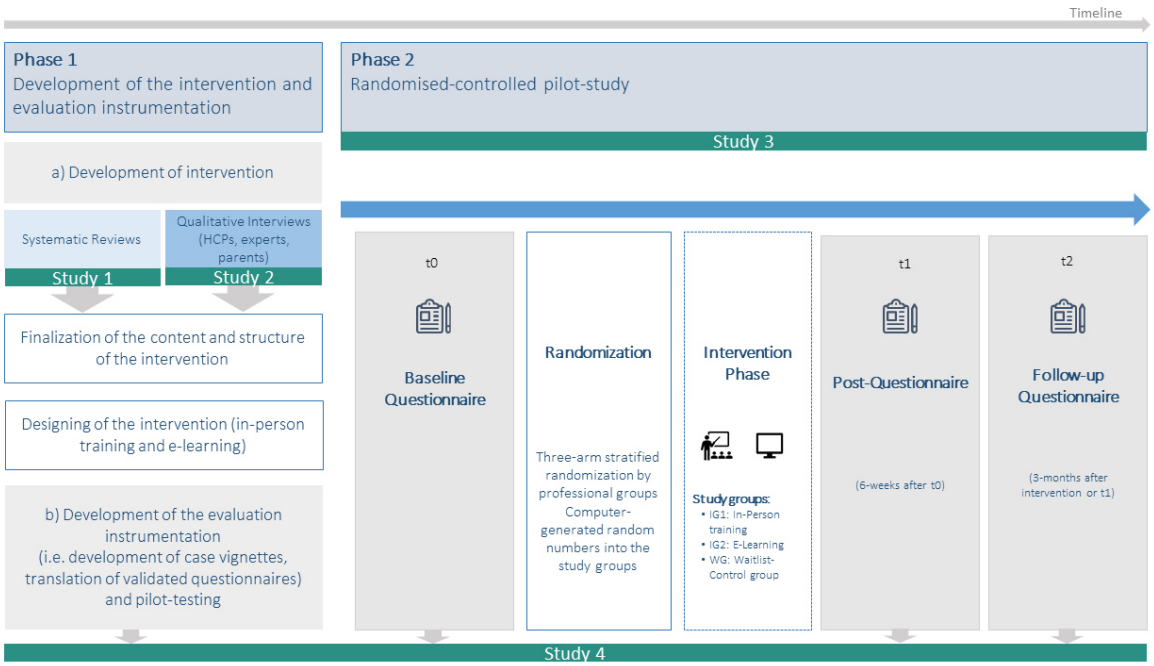

Figure 2. Overview of the KOMKEK study and its phases, alongside with four studies of this dissertation

Phase 1: In order to develop the training program, two systematic literature reviews and qualitative interviews were conducted. The first review addressed the question of which scientifically evaluated CST programs exist for oncology HCPs that integrate the topic of "cancer and parenthood". The second review examined study results on the impact of cancer on the mental health and well-being (including quality of life, levels of depression, and anxiety) of cancer patients with minor children. Additionally, qualitative interviews were conducted with three groups: oncology HCPs, experts in the field of "children of cancer-affected parents," and affected parents. Interviews focused on how family-oriented care for affected parents is perceived in the oncological context, what approaches are desired for care from various perspectives, and which aspects are relevant to the development of a training program for HCPs. The results from this phase were used to develop the training program, which resulted in a 3-hour intervention, delivered either in a face-to-face (F2F) format or via an e-learning (EL). The final intervention consisted of three modules (see Figure 3).

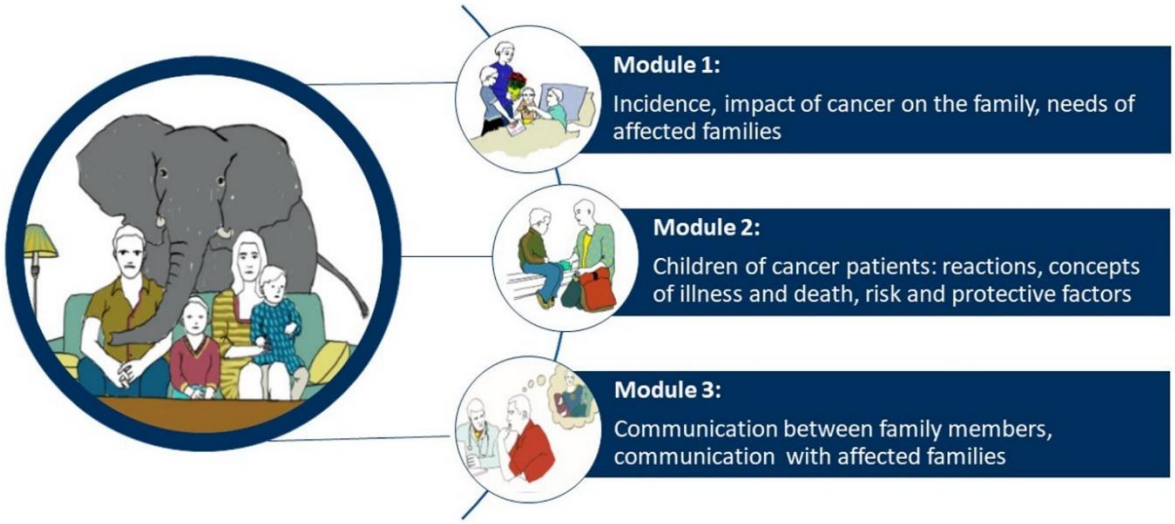

Figure 3. The 3-hour KOMKEK training program – overview of modules and content

Phase 2: In order to assess the intervention a three-armed pilot-RCT was conducted by comparing a F2F format with a self-directed EL and a waitlist-control group (CG). Beforehand, an evaluation instrument was developed, drawing upon the three levels of Kirkpatrick's model of program evaluation [125]. Existing assessment instruments were carefully selected by the research team and, when necessary, translated and adapted for research purposes using the team approach for translation (translation, review, adjudication, pretesting and documentation, TRAPD [126]). Additionally, specific instruments and items were developed for the research questions (including case vignettes, knowledge questions, and feedback on the intervention). Prior to its implementation in the pilot-RCT, both the intervention and the developed instruments were pilot-tested. The training was presented and discussed with a small group of various HCPs, and the developed instruments were pilot-tested through cognitive interviews with six HCPs [127]. In response to the COVID-19 pandemic and the associated contact restrictions in Germany starting in March 2020, the original face-to-face format was modified to an interactive web-based format. Detailed methods of the pilot-RCT will be described in the following section 3.2.3.

3.2. Methods of this dissertation

This dissertation is embedded in the context of both project phases of the above described study and therefore will contribute towards the development of the training and assessing its efficacy. In the following sections I will describe the methods addressing the individual four studies and their aims of this dissertation. The four studies are also displayed in Figure 2, corresponding to the underlying KOMKEK study and its phases.

3.2.1. Study 1: Systematic identification of CSTs incorporating "cancer and parenthood"

For **Study 1**, a systematic review (Publication 2), was registered with the International Prospective Register of Systematic Reviews (PROSPERO, registration code: CRD42020139783) and adhered to the PRISMA 2020 guidelines (PRISMA 2020 statement [128]). An electronic literature search was conducted across several databases, including PubMed, Cinahl, PsycInfo, and Web of Science, with no restrictions on publication year, utilizing keywords across the domains of 'communication skills training', 'healthcare professional', 'oncology', and 'parent/family'. The search was performed on December 9, 2020, including updates on December 3, 2021, and again on August 12, 2022. A liberian provided input to the search strategy to ensure accuracy. Eligibility criteria included peer-reviewed studies published in English or German that focused on any type of CST applying a pre-post design, addressing child- and parent-specific aspects in cancer care for HCPs working with adult cancer patients. As the initial search yielded only two applicable studies, the review was broadened to include additional studies with relevant child- and family-specific modules. Duplicates were removed using EndNote. A two-reviewer system was implemented for study selection and quality assessment. Findings were analyzed narratively, and outcomes categorized according to Kirkpatrick's training evaluation framework [125]. The quality of included studies was evaluated using a modified NIH assessment tool for pre-post studies without control groups [129].

3.2.2. Study 2: Qualitative interviews with HCPs

To answer the research questions of **Study 2** of my dissertation, a qualitative study was conducted (Publication 4), analyzing data from semi-structured interviews with n=20 HCPs working in oncology. The interview study took place at the University Medical Center Hamburg-Eppendorf (UKE) in Germany, with participants recruited through professional networks and snowball sampling in the greater Hamburg area, Germany. Eligible participants included physicians, nurses, psychologists, and social workers engaged with cancer patients in either outpatient or inpatient settings. Interviews were conducted face-to-face or by telephone from October 2018 to January 2019, guided by a semi-structured interview format developed by the research team. The interview format was pilot-tested within the first interview, but no changed were necessary afterwards.
Interviews covered themes related to HCPs' practices regarding child- and family-related aspects, perceived needs of families, and requirements for CSTs. All interviews were audio-recorded and transcribed verbatim using the f4transkript. The transcripts were then analyzed using qualitative content analysis based on Kuckartz [130] with MAXQDA software (Version 2020, VERBI GmbH, Berlin, Germany) through an iterative process that involved repeated cycles of coding, review, and

refinement. Ethical approval was granted by the Local Psychological Ethics Committee at the Medical Center Hamburg-Eppendorf, and informed consent was obtained from all participants.

3.2.3. Study 3: Evaluation of feasibility and effectiveness of a newly developed CST

To answer the research questions of **Study 3** of this dissertation, the feasibility and effectiveness of the KOMKEK intervention was evaluated within a three-armed pilot-RCT (Publication 3), including a study protocol being published before conducting the pilot-RCT (Publication 1). Study groups were compared regarding improvements in primary and secondary outcomes at three time points: baseline (t0), post-training (t1), and at a 3-month follow-up (t2). HCPs currently working in oncology were recruited from September 2019 to April 2021 via email and mail. Participants, regardless of their profession or setting, provided written informed consent prior to completing the baseline assessment. After baseline assessment, participants were stratified by profession and randomly assigned to the three study groups (F2F, EL, CG). Post-training assessments occurred shortly after training participation, followed by the 3-month follow-up assessment. Outcome measures were based on three levels of Kirkpatrick's model of program evaluation: reaction, learning, and behavior [125]. The primary outcome assessed HCP competence in addressing child- and family-related themes in cancer care, using an assessment tool specifically developed by the study team that combines clinical case vignettes and situational judgement tests [131]. Secondary outcomes included - among others - assessments of knowledge, self-efficacy in communication skills, and communication behavior regarding child- and family-related aspects of cancer care. All applied outcome measurements are displayed in Table 1. The statistical analysis included a power calculation that determined a necessary sample size of 108 participants, accounting for a 30% dropout rate, to achieve adequate power for detecting differences between groups. Non-parametric tests were employed to evaluate participants' training satisfaction and perform between-group comparisons. Additionally, linear mixed models with repeated measures were used to assess outcome improvements across study groups over time, accounting for baseline covariates, individual differences and descriptive statistics for baseline characteristics, participants' intervention expectations and training motivation.

3.2.4. Study 4: Development and psychometric assessment of the SE-12-G

To assess self-efficacy among HCPs in their communication competencies, a tool needed to be developed and psychometrically tested, which is the basis of the aim of **Study 4** (Publication 5). For this, the original SE-12 questionnaire [132], a unidimensional tool with 12 items, was first translated

into German using the TRAPD translation protocol [126, 133]. The translation involved two team members with relevant expertise independently translating the SE-12, followed by a review from a third, blinded member to finalize the translation. A consensus was reached through discussions among the researchers. Finally, cognitive interviews were conducted with six HCPs to evaluate the comprehensibility and feasibility of the SE-12-G, employing the think-aloud technique alongside verbal probing to gather insights on specific terms and phrases related to clinical skills [127]. The comments and suggestions gathered from these interviews led to minor modifications, confirming the measure's comprehensibility and content validity.

The development of the SE-12-G adhered to the COSMIN guidelines (consensus-based standards for the selection of health measurement instruments), ensuring rigorous psychometric assessment of its reliability and validity [134]. The approach was informed by the reflective model detailed by DeVet et al. [135], which emphasizes iterative testing and refinement throughout the instrument development process, allowing for robust evaluation and adaptation of the measure in alignment with the intended construct. The psychometric assessment was conducted through a secondary analysis of data from the KOMKEK RCT pilot-study (**Study 3**). The SE-12-G was included among the three measurement points to evaluate HCP competencies in addressing child- and family-related aspects in cancer care, alongside demographic variables. Data were entered into SPSS (IBM SPSS Statistics, V.27) with double entry protocols applied for quality control. For psychometric evaluation, descriptive statistics were calculated to describe the sample. Item analyses were performed for each subscale, including item means, standard deviations, and item-total correlations. The measures assessed both internal consistency using Cronbach's alpha and test-retest reliability using data from the CG. Content validity was explored through bivariate correlations between self-efficacy subscales and participants' experience levels. Factorial validity was evaluated using confirmatory factor analysis (CFA). Three hypothesized models were tested: a one-dimensional structure replicating the original SE-12 measure, a two-factor structure integrating the confidence and importance subscales, and an ordinal factor model treating importance variables as ordinal due to the non-normal distribution of the data. Fit indices, including the Comparative Fit Index (CFI) and Root Mean Square Error of Approximation (RMSEA), were examined to assess model fit. The analyses detailed adaptive measures to handle missing data and ensure the robustness of insights gained from the SE-12-G psychometric testing.

Table 1. Outcomes, applied measures according to Kirkpatrick within the RCT pilot-trial

Outcome	Measure	Level of Kirkpatrick's model [125]	Measurement time point		
			T0	T1	T2
Demographic and occupational variables	Self-developed items	n/a	x		
Changes in sociodemographic or occupational situation	Self-developed items	n/a		x	x
Primary outcome					
Competency to address child- and family-related aspects	Self-developed clinical case vignettes and situational judgement tests [131]	Level 3: Behaviour	x	x	x
Secondary outcomes					
Satisfaction with the training	Self-developed items	Level 1: Reaction		x	x[a]
Knowledge regarding child- and family-related aspects	Self-developed items	Level 2: Learning	x	x	x
Self-efficacy in and attitudes towards clinical communication skills	SE-12-G, translated and adapted from the SE-12 questionnaire [132]	Level 2: Learning	x	x	x
Self-efficacy in and attitudes towards specific child- and family-related communication skills	SE-fam, translated and adapted from the SE-12 [132] and an instrument about existential issues [136]	Level 2: Learning	x	x	x
Communication and attitudes regarding child- and family-related aspects in daily work	Self-developed items	Level 3: Behaviour	x	x	x
Covariates & additional outcomes					
Professional fulfillment and burn-out	Professional Fulfillment Index, translated and adapted to the German context [137]	n/a	x	x	x
Interprofessional teamwork	Self-developed items	n/a	x	x	x
Barriers to integrate child- and family-related aspects into daily work	Self-developed items	n/a	x	x	x

Abbreviations. T0: Baseline (before randomization); T1: Post-assessment (after the training for IG / 6-weeks-follow up for CG); T2: Follow-up (3-months after intervention or T1); n/a: not applicable. [a]only the participants of the CG, as they could participate in a training of their choice after T1 assessment.

4. RESULTS

The results of the four studies of this dissertation with their individual aims and research questions are presented below along with its related five publications. The subsequent section offers a structured summary of these studies, with the full texts of the related publications available in section 11.

4.1. Study 1: Systematic identification of CSTs incorporating "cancer and parenthood"

Related publication | Publication 2:

Frerichs W, Geertz W, Johannsen LM, Inhestern L & Bergelt C. (2022). *Child- and family-specific communication skills trainings for healthcare professionals caring for families with parental cancer: A systematic review.* PLoS One, 17(11): e0277225. doi: 10.1371/journal.pone.0277225.

Aim

This systematic review aims to evaluate CSTs designed for HCPs working in oncology, specifically including a child- and family-specific module, their outcome measures, and effectiveness.

Methods

A systematic database search was employed in electronic databases (PubMed, Cinahl, PsycInfo, and Web of Science) initially in December 2020, with an update in December 2021 and August 2022, employing keywords related to 'communication skills training,' 'healthcare professionals,' 'oncology,' and 'parent/family.' Studies were included if they met pre-defined criteria: being published in English or German, examining any form of CST, used a pre-post design and addressed child- and family-specific aspects in cancer care for HCPs. Due to the varied nature of the included studies, meta-analysis was not feasible and the scope was broadened after initial findings only identified two relevant studies. Duplicates were managed using EndNote and two independent reviewers performed study selection and quality assessment. Findings were narratively synthesized and categorized per Kirkpatrick's framework, while the quality of included studies was assessed using a modified NIH tool for pre-post studies without control groups.

Results

Nine studies were included that examined CST interventions relevant to cancer patients with minor children. All included studies were published between 2008 and 2021, predominantly from North America, with various methods and groups of participants (nurses only versus multidisciplinary; small groups with up to eight participants versus large groups with up to 158 participants). A total of 1,578 HCPs were included - mostly experienced professionals and females - with a significant representation of nursing staff. Methodological designs varied in the included studies; the majority employed pre-post assessments without control groups. CST programs utilized diverse formats, including EL, webinars, and face-to-face training over durations ranging from 30 minutes up to two days.

Outcomes tools used included assessment of HCPs' competencies in approaching family-related topics, self-efficacy in communication, and knowledge improvement. The results demonstrated a predominantly positive participant satisfaction level with the training, as well as statistically significant improvements in self-reported communication skills and knowledge, although changes in observed behavior were less consistently reported. Methodological quality varied, with most studies rated as "fair" or "poor," indicating a need for improved rigor in study design and reporting.

Conclusion

Findings of this published systematic review highlights the urgent need for specialized CST focused on parental cancer. The review reveals that only two studies specifically addressed this area, while the remaining studies offered limited family communication modules, underscoring the necessity for further development and thorough evaluation of tailored CST programs. Future research should prioritize rigorous evaluation of CSTs, especially those that clearly detail family-related content, to better equip HCPs in meeting the unique needs of this patient population.

4.2. Study 2: Exploring HCP communication practice in cancer care

Related publication | Publication 4:

Frerichs W, Johannsen LM, Inhestern L & Bergelt C. (2025). *Providing care to cancer patients parenting minor children: a qualitative study on healthcare professionals' communication practice.* Patient Education and Counseling Jan 13;133:108666. doi: 10.1016/j.pec.2025.108666.

Aim

This study aimed to explore HCPs experiences and attitudes regarding the communication of child- and family-related aspects in cancer care in Germany.

Methods

A qualitative study was conducted through semi-structured interviews with 20 HCPs, including physicians, nurses, psychologists, and social workers from the greater area of Hamburg, Germany. A semi-structured interview guide explored HCPs current practices and experiences in cancer care related to child- and family-specific aspects and their attitudes towards the importance of these themes. Data were analyzed via qualitative content analysis by Kuckartz, following the Standards for Reporting Qualitative Research guidelines.

Results

20 HCPs participated (n=7 nurses, n=6 psychologists, n=5 physicians, n=2 social workers) of which 85% were females and their mean years of professional experience working in oncology was 10.7 years. Findings revealed that HCPs revealed diverse experiences and attitudes towards addressing child- and family-related aspects in cancer care. Participants highlighted the necessity for HCPs to inquire about parental status and assess the psychosocial needs of cancer patients, with many expressing uncertainty on how to initiate these conversations. While some HCPs offered advice on communicating with children about cancer, others felt inadequately prepared to do so. Additionally, referrals to specialized support services were discussed among HCPs, indicating a recognition of their role in guiding families through cancer treatment.

The attitudes of HCPs towards the relevance of discussing child- and family-related aspects varied significantly. Some viewed these conversations as low priority, focusing instead on immediate medical concerns, while others recognized their importance as integral to comprehensive cancer care. Notably, some HCPs acknowledged that families, particularly children, should be included in discussions about parental illness, believing that open communication could alleviate emotional distress and facilitate better coping mechanisms.

Conclusion

Findings of this publication reveal that HCPs show a wide range of attitudes and experiences regarding the communication of child- and family-related aspects in cancer care, with some actively engaged while others struggle due to factors such as lack of confidence and perceived limitations of their professional scope. This qualitative study highlights the necessity of integrating family-centered care into all healthcare settings by incorporating systematic screening for parental status and facilitating referrals to specialized support services. To enhance HCPs' competencies and optimize interprofessional collaboration in addressing psychosocial issues related to parental cancer, targeted training programs are essential, along with further research to identify barriers and enhance understanding of HCPs' communication practices.

4.3. Study 3: Evaluation of feasibility and effectiveness of a newly developed CST

The results of study 3 are divided into the two distinct publications, namely the study protocol of the pilot-RCT as well as the evaluation of the study itself.

Related publications |

Publication 1: Inhestern L, **Frerichs W**, Johannsen LM, Bergelt C. (2019). *Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot-study.* BMJ Open, 9(10):e032778. doi: 10.1136/bmjopen-2019-032778.

Publication 3: Johannsen LM*, **Frerichs W*,** Philipp R, Inhestern L, Bergelt C. (2023) *Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study.* Psychooncology. 32(10):1567-1577. doi: 10.1002/pon.6207. * Shared authorship.

Aim

The study aimed to pilot-test the intervention's feasibility and effectiveness, hypothesizing that trained HCPs would show greater improvement over time compared to untrained HCPs. The objective of the study protocol was to outline the phase two of the KOMKEK pilot-study, by providing a clear scientific framework that facilitates rigorous evaluation, minimizes biases, and allows for replication by other researchers in the field. Publishing detailed methodologies prior to conducting the pilot-study enhances transparency and accountability.

Methods

The study protocol was designed in accordance with the SPIRIT guidelines, ensuring all recommended elements for clinical trial protocols were addressed described the development and content of training interventions, which are based on an extensive review of the literature and insights gained from semi-structured interviews with patients and HCPs. The final F2F training consisted of three modules that covered the impact of parental cancer on families, children's developmental responses to parental illness, and effective communication strategies. This training was delivered in small groups by experienced trainers and incorporated various instructional methods, including lectures, discussions, and role-play. The EL mirrored the content of the F2F training, allowing HCPs to engage in self-directed learning at their convenience.

To evaluate the feasibility and effectiveness of the KOMKEK intervention, the study utilized a three-armed pilot-RCT comparing a F2F intervention with an EL and a CG. HCPs in oncology were recruited from September 2019 to April 2021, initially in the greater Hamburg area, and later throughout all of Germany. However, due to the COVID-19 pandemic starting in March 2020, the F2F format had to be adapted to a web-based format. After providing informed consent and baseline assessment (t0), participants were randomly and stratified by their profession assigned to one of three groups (F2F, EL, or CG). Post-training assessment (t1) was performed approximately 3 weeks after F2F training participation, 6-8 weeks after EL access, or for CG 6 weeks after baseline assessment. Participants of the CG group could participate in either EL or F2F (own choice) after t1. Outcomes were measured based on three levels of Kirkpatrick's evaluation model (reaction, learning, and behavior). The main outcome was HCPs competency in addressing child- and family-related aspects in cancer care, while secondary outcomes included among others knowledge and self-efficacy in communication skills (SE-12-G) as well as child- and family-related communications skills (SE-fam), communication and attitudes regarding these child- and family-related aspects in daily work, and professional fulfillment as co-variate (see Table 1 for more details). Statistical analysis included a sample size calculation of 108 participants, non-parametric tests, and linear mixed models for outcome comparison and intervention effect analysis.

Results

152 HCPs participated (38% psychologists, 26% physicians, 18% nurses, 10% social workers and 8% other HCPs), of which most were female (89%). Regarding level 1, both F2F and EL groups reported high satisfaction with the training with both training formats, with no statistical significant differences observed between F2F and EL participants; both formats were viewed as supportive, feasible, and acceptable. However, when asking about HCPs' preferences for training formats at follow-up (see Supplement 4d within Publication 4), the preference for F2F formats was higher (64%) compared to preferences for EL (22%), especially among nurses (75% for F2F) and physicians (71% for EL) compared to psychologists (32% for F2F). In terms of effectiveness, the primary outcome analysis revealed no statistical significant differences in competency related to child and family themes over time across study groups. However, F2F training showed statistical significant greater improvements in knowledge compared to CG from baseline to post-training and compared to EL at the three-month follow-up. Furthermore, both F2F and EL participants exhibited enhanced self-efficacy in communication skills (SE-12-G) and in child-and family-related communication skills (SE-fam) compared to CG. Additionally, intervention groups statistical significantly increased their

communication behaviors about child- and family-related aspects in daily work, such as discussing children's needs and emotional impacts, particularly in the F2F format.

Conclusion

Findings of this third study showed no improvements in HCPs' competencies related to child- and family-specific themes, but statistically significant increases in knowledge, self-efficacy, and family-oriented communication, with participants favoring F2F training. However, as HCPs face time constraints and other barriers to participating in F2F interventions, EL should be considered as a more flexible and suitable approach. Refresher courses are suggested for long-term enhancement, alongside the need for further research to validate these findings. Additionally, tailored adaptations might be necessary to accommodate varying professional backgrounds and experiences.

4.4. Study 4: Development and psychometric assessment of the SE-12-G

Related publication | Publication 5:

Frerichs W, Johannsen LM, Inhestern L & Bergelt C (submitted 2024). *The German version of the self-efficacy questionnaire (SE-12-G) in a sample of healthcare professionals: Translation and psychometric properties*, 16 September 2024, PREPRINT (Version 1) available at Research Square [https://doi.org/10.21203/rs.3.rs-4836626/v1].

Aim:

This study aimed to translate the Self-Efficacy Questionnaire (SE-12) into a German, to adapt it to our purpose (SE-12-G) and to assess its psychometric properties.

Methods:

To evaluate self-efficacy in communication among HCPs, the SE-12 questionnaire was translated into German using the TRAPD protocol, involving independent translations by two team members and a consensus review by a third, blinded member. Cognitive interviews with six HCPs assessed the comprehensibility and feasibility of the SE-12-G, utilizing think-aloud and verbal probing techniques to gather feedback, which led to minor adjustments while confirming the measure's validity. The psychometric assessment was conducted as a secondary analysis using data from the KOMKEK pilot-RCT, where the SE-12-G was included at three measurement points to evaluate HCP competencies regarding child- and family-related aspects in cancer care. Descriptive statistics and item analyses assessed sample characteristics and scale reliability. Confirmatory factor analysis was performed to evaluate factorial validity, testing three models to examine the structure of self-efficacy components.

Results:

The development of the SE-12-G resulted in two sub-scales: the first assessing HCPs' confidence in their communication skills, the second sub-scale assessing the perceived importance scale, evaluating the same 12 items using a 5-point Likert scale (ranging from '1: not important at all' to '5: very important'), with both including a checkbox labeled 'not relevant'. The content validity of the SE-12-G confirmed clear comprehension of the items and response options. Participants' feedback indicated that the language and content were relevant and appropriate, validating the instrument's ability to effectively measure self-efficacy in communication skills among various HCPs. SE-12-G item analysis revealed that between 5.3% and 6.6% of participants considered specific items "not relevant," with missing values ranging from 1.3% to 2%. Participants answered over 98%

of items, indicating high engagement. Statistically significant ceiling effects were observed on the confidence scale for 6 items (range 15.8%-30.3%) and on all items of the importance scale (range 54.6%-85.5%). Corrected item-total correlations for the confidence scale ranged from 0.46 to 0.66, and for the importance scale from 0.34 to 0.62, suggesting strong associations for items 3 and 10, while item 4 and item 1 showed weaker links. The internal consistency was robust (Cronbach's alpha α=0.88). Test-retest reliability showed considerable correlation (r=0.725 for confidence, r=0.726 for importance). Convergent validity exhibited weak correlations with work experience related to cancer care (r=0.147 for confidence). Responsiveness revealed a moderate effect size for the confidence scale (Cohen's d=0.77) but limited change sensitivity for the importance scale (Cohen's d=0.25). Factor analysis confirmed model fit, yet AVE values indicated inadequate latent construct representation. Overall, the SE-12-G demonstrates good reliability and validity but requires refinement to enhance its measurement efficacy.

Conclusion:

The paper on the development and psychometric properties of the SE-12-G represents the first valid and reliable measure for assessing the self-efficacy of HCPs in communication skills in German, although further modifications and evaluations in a larger, more diverse sample are necessary due to the identified psychometric limitations.

5. DISCUSSION

This dissertation investigated the communication practices of HCPs when interacting with parents affected by cancer, drawing on findings from the four individual studies presented in five distinct publications. The discussion of these results is organized according to the MRC framework for developing and evaluating complex interventions [119]. This approach aligns with the context of implementation research and the four phases of the MRC framework, each corresponding to at least one of the four studies conducted within this dissertation (see Figure 4 for details).

Phase 1: The Development of the Intervention. To address the first MRC phase, this dissertation integrates results from **Studies 1** and **2**, which inform the conceptualization of the intervention by synthesizing empirical evidence of existing CSTs for HCPs in oncology and HCPs' perspectives on the subject of child- and family-related aspects in cancer care. Addressing the first aim in **Study 1**, findings of the systematic review highlight that only two out of nine included studies specifically addressed "cancer and parenthood" within their CST. Additionally, training formats of the included studies varied greatly, as well as outcome measures. Eight studies reported statistically significant enhancements in communication skills following the training, but the quality of most studies was fair. Thus, the results of **Study 1** highlight the need for a training tailored to HCPs communicating with parents affected by cancer as well as the effectiveness of such programs. According to the aim of **Study 2,** the analysis of the qualitative interviews with 20 HCPs working in oncology provides insights into HCPs' experiences when communicating about child- and family-related aspects in cancer care and their attitudes about the importance of including these. Findings indicate that HCPs' experiences and opinions towards integrating child- and family-related aspects into cancer care vary widely, influenced by factors such as professional roles and individual beliefs. These results contribute to a refined understanding of the necessary components for a needs-based and specific training program, thus informing the intervention development process of **Study 3**.

Phase 2: Feasibility and Pilot Testing of the Intervention. In line with Phase 2 of the MRC framework, a secondary aim of **Study 3** was to evaluate the feasibility and initial testing of the developed training intervention through a pilot-RCT. Accordingly, a study protocol (Publication 1) was published. It provides a detailed outline of **Study 3**, namely the development and evaluation of a training program for HCPs in oncology aimed at enhancing HCPs competencies in caring for patients with minor children by applying a three-armed pilot-RCT (F2F training versus EL versus CG). Participants in both intervention groups (F2F and EL) reported high satisfaction levels with the training content and delivery. The economic considerations associated with implementing both

training formats were also considered, with flexibility of the EL format enhancing resource allocation and accessibility across diverse healthcare settings and regions.

Phase 3: Evaluation of the Intervention. Building on the development and feasibility assessment, Phase 3 of the MRC framework included the evaluation results reported in **Studies 3** and **4**. The aim of **Study 3** was to evaluate the feasibility and effectiveness of the developed training program within a pilot-RCT. Despite the absence of statistically significant differences in the primary outcome of the pilot-RCT (**Study 3**), there were positive trends in the secondary outcomes over time, namely in knowledge and self-efficacy, which suggested opportunities for further refinement and research. Addressing the fourth aim in **Study 4**, the Self-Efficacy Questionnaire (SE-12) - an instrument measuring HCPs' confidence in various communication skills - was translated into German and adapted, resulting in the instrument 'SE-12-G'. Additionally, the psychometric properties of the SE-12-G were assessed through a secondary analysis of data from **Study 3**. The high validity and internal consistency scores confirm that the SE-12-G effectively captures HCPs' communication competencies. The identification of ceiling effects on certain items points to yet another area of uncertainty within the measurement design. The results of **Studies 3** and **4** within this MRC phase underscore the need for ongoing refinement of both the assessment tools and the intervention itself, ensuring that they accurately reflect the outcomes of interest. Additionally, evaluating the comparative resource and outcome consequences of the intervention aids in justifying continued investment in training development.

Phase 4: Implementation. The final phase encompasses the implementation of the intervention, which was not a formal aim of this dissertation. However, by making the training accessible through an EL platform and the F2F training material through the webpage of the funder of the KOMKEK study [123], this final step towards Phase 4 of the MRC framework contributes to enhancing accessibility and practical translation of the intervention into routine practice, addressing various oncology settings as well as learning preferences among HCPs.

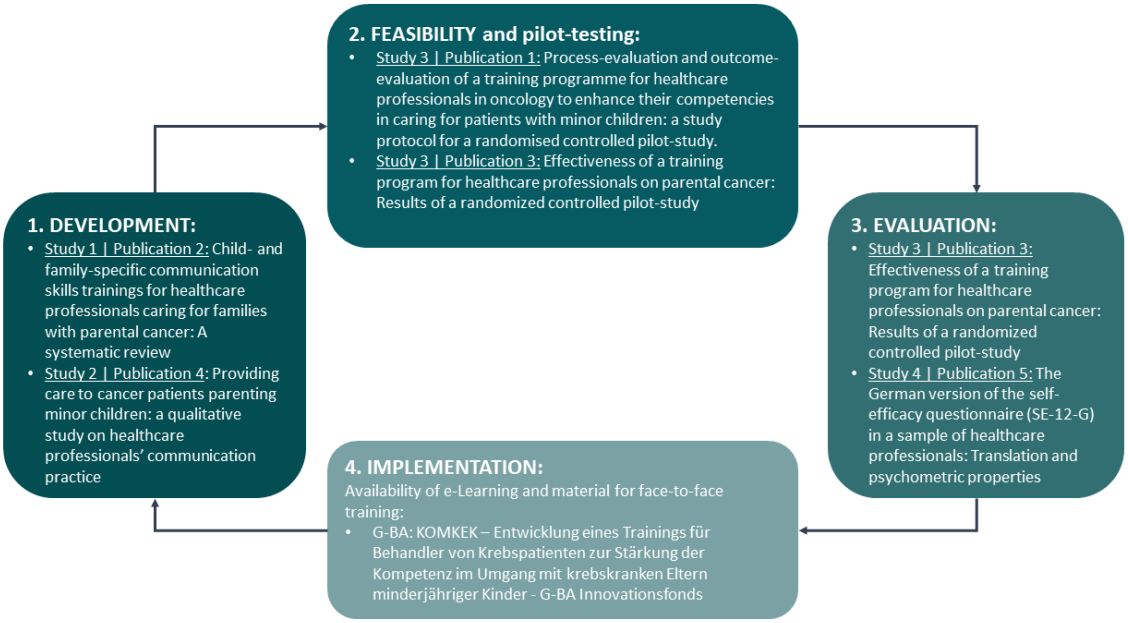

Figure 4. Integration of the results of this dissertation into the MRC framework for developing and evaluating complex interventions [119]

5.1. Comprehensive discussion

The results of this dissertation significantly contribute to addressing the research gaps described in section 2 by providing both international and national perspectives on communication skills, as well as insights into the knowledge and views of HCPs who provide supportive care to parents with cancer.

The results of **Study 1**, conducted as a systematic review, revealed a lack of specific CSTs for HCPs on addressing child- and family-related aspects in cancer care, despite a high need and relevance. Additionally, existing CSTs, which were included in the analysis, demonstrated methodological deficiencies, particularly in terms of reporting (e.g., sample size calculation and eligibility criteria) and the use comprehensive outcome assessments. These findings align with prior research that highlight a deficiency in CSTs within oncological care. Although CSTs have become partially mandatory for HCPs working in oncology [113] or HCPs with patient contact [138], and numerous CSTs have been developed and evaluated over the past 20 years – including through RCTs [111, 115] - there has been only minimal progress in enhancing patient-centered communication between oncologists and patients [139]. Further, there is still a significant lack of CSTs addressing specific topics in cancer care. This includes critical areas such as early conversations about palliative care and end-of-life issues [140, 141] as well as strategies for communicating with patients about

prognosis, emotion and serious illness communication [142]. This deficiency indicates a broader concern within oncology. Effective communication in cancer care is particularly challenging due to the complexities of individual treatment options and the frequently uncertain outcomes associated with the risk of cancer recurrence [111], compounded by the serious nature of the illness. Therefore, it is crucial that HCPs can adapt their communication to the patient's emotions, needs and preferences [143-145], including identifying and addressing emotional and psychosocial support using a family-centered approach. Similar to the results of **Study 1** of this dissertation, previous research has identified significant variability among existing CSTs in oncology regarding their types, training duration, outcome measures, and overall methodological quality [111, 113, 114]. This variability makes it challenging to draw definitive conclusions about the relative effectiveness of different programs. Consequently, along with other researchers [114, 115, 142], the results of the systematic review (**Study 1**) underscore the importance of employing advanced methodologies, including validated and pilot-tested measures in accordance with Kirkpatrick's evaluation framework [125] for the implementation of high-quality evaluations of future CSTs. Within the results of **Study 1**, a significant portion of the participants of the included studies were nurses, with six studies focusing only on this group [105, 146-150] and two involving them primarily [151, 152]. Given that nurses invest a substantial amount of their time caring for patients and fostering relationships with patients and their families [153], they are particularly attuned to addressing specific patient needs and providing emotional support [154]. Additionally, nurses are perceived as willing and capable of managing the psychosocial care of cancer patients with minor children [96, 154-156]. So far, qualitative research has also primarily focused on nurses' perspective on communication practice when cancer patients parent minor children [108, 154]. Thus, **Study 2** of this dissertation addresses a critical gap in the literature by presenting the diverse experiences of various HCPs in cancer care within the German context, specifically focusing on communication regarding child- and family-related aspects in cancer care. Importantly, results of **Study 2** not only highlight the differences in experiences and attitudes among HCP groups but also synthesizes these findings to provide a comprehensive understanding of how these perspectives influence communication practices in clinical settings and between healthcare groups. The findings reveal that both nurses and physicians experience higher levels of uncertainty when addressing these aspects compared to (psycho-)social HCPs. Furthermore, the nurses and physicians participating in **Study 2** expressed the belief that advising on and communicating about child- and family-related aspects do not fall within their professional role. This perspective aligns with previous research indicating that HCPs in acute settings often assume that parental needs at the end of life are addressed by community teams [107], that HCPs would not be rewarded for providing psychosocial

care [94], and that discussions around family dynamics would be typically undertaken by other healthcare staff, particularly nurses [35]. Also, in a qualitative study exploring cancer parents family-centered cancer care experiences, participating parents expressed concerns regarding HCPs insecurities about their responsibilities related to psychosocial issues and family matters [96]. This trend highlights a tendency in the healthcare system to defer responsibility for family-related communication to others, emphasizing the need for multidisciplinary CSTs in oncology [157], which should include clarifying the roles and responsibilities of various the HCPs to facilitate effective interprofessional collaboration and communication [158]. The reported differences in **Study 2** regarding the perceived communication competencies and practices between clinicians (nurses and physicians) and (psycho-)social staff (such as psycho-oncologists and social workers) are not surprising, as their education and daily responsibilities vary. (Psycho-)social staff tend to focus more on identifying and addressing the psychosocial needs of patients, while nurses and physicians primarily concentrate on medical care and clinical responsibilities [94, 159]. Nonetheless, as clinicians - especially oncologists - are usually the first point of contact when a patient receives a cancer diagnosis, they serve as a 'gatekeeper' in identifying cancer patients who are parents of minor children, their specific needs and worries, and possibly refer to specialized psychosocial care [65]. Psycho-oncological support is recognized as an essential component of comprehensive cancer care and should be provided by all HCPs involved in cancer care [74]. Still, the results of this **Study 2** show great variability in assessing parental status and communication about child- and family-related aspects in cancer care, which is partly influenced by HCPs' individual characteristics and attitudes. This result is in line with previous research. For instance, Johannsen et al. found that HCPs who are parents themselves are more likely to recognize and prioritize parental involvement in cancer care compared to those who do not have children [96]. Lastly, results of the **Study 2** indicate that HCPs lack confidence and communication skills and feel inadequately prepared for communicating about child- and family-related aspects in cancer care, which is in line with wider research [94, 107, 154, 160].

In summary, the results of **Study 1** and **Study 2** of this dissertation underscore the critical need for a specific communication training to support HCPs in addressing child- and family-related aspects in cancer care. Additionally, these findings inform the content of developing such a training, aiming at enhancing HCPs knowledge, skills and confidence using advanced methodologies and validated, pilot-tested measures in accordance with Kirkpatrick's evaluation framework [125].

In light of these findings, **Study 3** incorporated Kirkpatrick's framework into the design and evaluation of the developed training intervention, highlighting the critical need for a structured approach to systematically assess its impact on HCPs' knowledge and self-efficacy. By developing

two intervention formats – a F2F format that was adapted to a web-based format due to the onset of the COVID-19 pandemic in March 2020, and an EL format - both formats were tested in a pilot-RCT including a CG. This approach enabled the assessment of the feasibility and effectiveness of each training format among various groups of HCPs. Previous research has shown that online medical education during COVID-19 was effective [161], with students reporting statistically significant time savings [162] and finding the format more convenient and comfortable, allowing them to learn at their own pace [163]. The results of **Study 3**, regarding the feasibility of the newly developed training program showed that participants consistently viewed both formats as supportive, feasible, and acceptable. In terms of effectiveness, only one small statistically significant difference was found between the two formats: F2F group exhibited statistically significant higher improvements in *knowledge* compared to the EL group when comparing baseline and follow-up measurement. However, both formats demonstrated various statistically significant improvements compared to the CG in secondary outcomes including, self-efficacy in communication skills (SE-12-G), self-efficacy in child- and family-related communication skills (SE-fam), and communication about these aspects in daily work. These findings suggest similar effectiveness between the two training formats. Still, higher dropout rates and participants' feedback reflect a stronger preference for the F2F format. However, as HCPs face various challenges in their daily clinical routines that may hinder participation in F2F interventions, such as time constraints [114], EL presents a viable alternative due to its flexibility [114]. Nonetheless, limited evidence regarding patient-reported outcomes from EL interventions necessitates careful consideration of its advantages and disadvantages when designing training programs for HCPs. Previous research has indicated that online education elicits a wide range of beliefs, feelings, and experiences regarding its effectiveness, quality, and best educational practices [164]. Despite these concerns, location-independent training formats - including self-directed EL, web-based training, and blended learning - can provide a valuable alternative, particularly in post-graduate CST. Potential barriers to effective CSTs include historically limited access for HCPs due to the delayed integration of CST into the medical curriculum [165], and the expectation that certain oncology disciplines, such as nursing, develop these skills through on-the-job experiences [166]. Moreover, restricted training availability, challenges in accessing F2F sessions, time commitments, and associated costs highlight the increasing value of EL resources [114]. In summary, **Study 3** demonstrates that both training formats are similarly feasible and effective in enhancing HCPs competencies to support cancer patients who are parenting minor children. However, challenges such as time constraints and barriers to participation pose significant obstacles to consistent implementation. Given these factors, the established EL intervention emerges as a valuable and easily accessible resource for all German-speaking HCPs

working in oncology, effectively addressing these challenges and promoting enhanced communication and support for affected families. Therefore, while both training formats have their merits, the decision on the “right” format should consider HCPs’ needs, the context of their professional development, as well as the resources of their educational institution. In order to assess HCPs’ self-efficacy in their communication competencies as part of the effectiveness of the pilot-RCT in **Study 3**, the German version of the Self-Efficacy Questionnaire (SE-12-G) was developed and psychometrically tested within **Study 4**. The results provide good values for acceptance and reliability, but high ceiling effects - particularly within the importance scale - could hinder the detection of more statistically significant training effects in **Study 3** [167, 168]. The result of the high ceiling effects is similar to the results of the psychometric assessment of the original SE-12 measure by Axboe et al. [132] and the Spanish version [169]. While the SE-12-G successfully captured changes in confidence and importance scale scores post-training, weak correlations with working experience were found, contrary to the original SE-12 findings by Axboe et al. [132], suggesting a need for future studies incorporating other measurements to assess convergent validity [93, 169]. Additionally, sampling and volunteer bias may have influenced the data, as participants of **Study 3** voluntarily participated in a CST focused on child- and family-specific aspects in cancer care, thus were likely to be highly motivated and interested in the topic, possibly explaining the observed high ceiling effects. To ensure generalizability, further validation in diverse settings that do not involve participation in a CST program is essential, as currently being conducted in a RCT focused on improving patient-centered communication skills among nursing professionals [170].

5.2. Research implications

The findings from the four studies in this dissertation highlight several key implications for future research regarding the enhancement of HCPs communication with cancer patients with minor children.

First, future studies should incorporate rigorously developed training content grounded in implementation research, such as the MRC framework and the current recommendations in this dissertation. Alongside previous research, results from **Studies 1**, **2** and **3** indicate that future CSTs should be applicable to a broader range of HCPs (currently they are often limited to nurses) and integrate strategies for interprofessional collaboration [158], particularly focusing on the competency of "roles and responsibilities" when a parent has cancer, as noted in **Study 2**. While role-play exercises and recorded consultations with feedback have shown promise in enhancing the effectiveness of CSTs, they were not included in the interventions of **Study 3** for various reasons. Future studies could adopt a novel approach by incorporating real HCP-patient interactions within

the intervention delivery, followed by structured feedback sessions, as proposed by Antonsen et al. [171].

Additionally, as post-training follow-up is recommended [172] and demonstrates potential significance in effectiveness [173]. Future studies should consider incorporating booster sessions or feedback opportunities to promote sustainability after participation, or include a specifically trained peer trainer within the department to foster the implementation of CST content [172] .

Second, future studies evaluating and implementing CSTs for enhancing HCPs' communication competencies and knowledge regarding parenthood and cancer should employ EL and/or blended learning formats. These formats may help to overcome barriers to CST implementation such as high costs or organizational and time issues with F2F formats.

Third, results of all four studies of this dissertation emphasize the need for rigorously developed studies that include a control group and use specific frameworks for training evaluation, such as Kirkpatrick's framework [125]. Additionally, there is a need for standardized measures to assess communication [142] as identified in **Studies 1 and 4**, especially validated tools that specifically assess communication skills related to child- and family-specific aspects of cancer care are rare [73, 105, 152]. Along with previous research [114, 174], these results of this dissertation suggest that future interventions should undergo formal evaluations to address the methodological issues of limited previous studies. To enhance the validity of future studies, researchers should base their measurements on psychometrically sound instruments and assessment methods grounded in Kirkpatrick's training evaluation, including patient-reported outcomes (level 4, patient's satisfaction and information provided during the consultation), as this is often overlooked [114, 175]. Additionally, incorporating objective standardized patient assessments (SPAs) as the gold standard for evaluating CSTs, along with standardized clinical case vignettes that have demonstrated comparability to SPAs, will further improve the robustness of these evaluations [131, 176].

Fourth, future implementation studies should include a thorough process evaluation throughout the implementation of the intervention, as this is crucial for understanding the mechanisms through which interventions are delivered and received. So far, few studies have quantitatively assessed the hindering and promoting factors in the implementation of training initiatives, although qualitative research has offered valuable insights into the barriers and facilitators encountered in applying learned skills [120, 121]. A comprehensive process evaluation, aligned with frameworks such as the Consolidated Framework for Implementation Research (CFIR [177]) or the MRC framework [119], allows researchers to identify the implementation itself (e.g., dose, fidelity and adaption), mechanisms of intervention impact (e.g., participant and stakeholder responses) and contextual factors influencing implementation outcomes. This process allows gathering insights into the

experiences of both HCPs and possibly patients. This understanding not only aids in optimizing the intervention but also guides the adaptation of strategies for future implementations, thereby enhancing the sustainability and effectiveness of evidence-based practices in healthcare. Therefore, it should be integrated into new studies evaluating CSTs as a fundamental aspect of implementation research.

Fifth, while the results of **Study 2** provide valuable insights into HCPs' current practices in cancer care through self-reported data, further qualitative studies are essential to uncover the barriers and facilitators that various HCPs encounter when implementing family-centered cancer care. For instance, incorporating direct observations of HCPs delivering care to cancer patients alongside self-reported data would significantly enrich our understanding of actual communication behaviors and practices within the context of cancer care.

Finally, results of **Study 4** indicate that the SE-12-G instrument should be further refined and evaluated among larger, more heterogeneous samples of HCPs not involved in specific intervention programs. This will help establish a more comprehensive understanding of its applicability and relevance across different settings. Given that the sample of **Studies 3** and **4** included a significant number of psychosocial HCPs who were highly motivated to participate in CST, further application of the SE-12-G in diverse HCP samples is necessary to assess potential ceiling effects. Additionally, the voluntary nature of participation introduces selection and voluntary bias, which can impact findings and contribute to high ceiling effects. As highlighted in **Study 1** of this dissertation, there is a scarcity of validated assessment measures specifically addressing communication skills related to child- and family-specific aspects of cancer care [73, 105, 152]. For the purpose of the aim of **Study 3**, the SE-12-G has been further adapted with five additional items assessing HCPs' self-efficacy towards child- and family-related communication skills (SE-fam). Assessing the psychometric properties of the SE-fam measure will provide validated tools for future outcome studies focusing on CSTs in child- and family-related contexts.

5.3. Practice implications

According to estimates from the Robert Koch Institute, approximately 50,000 children in Germany are impacted by parental cancer each year [178], although actual numbers may be higher due to a lack of systematic screening. Cancer significantly affects the mental health of parents with minor children [28], making it crucial for HCPs in oncology to screen for parental status and distress. This screening is essential not only to enhance treatment outcomes for these parents but also to support the well-being and psychosocial adjustment of their children. Findings from **Study 2** of this dissertation indicate that clinical practice varies widely concerning routine screenings for parental

status and specific needs. Therefore, it is imperative to implement systematic screening alongside effective referral strategies to family- and child-centered support services to ensure comprehensive cancer care.

Currently, only 57 specialized support services exist in Germany for affected families [179], with limited availability in rural areas. This underscores the urgent need for all HCPs in oncology to possess at least basic knowledge and skills to provide essential support to these families. Many parents express a desire for information, guidance, and support on communicating with their minor children about life-limiting illnesses like cancer [65, 96]. Therefore, HCPs should ensure the distribution of accessible resources, such as booklets, tailored to the needs of those affected by parental cancer.

The newly developed and evaluated 3-hour intervention described in **Study 3** of this dissertation serves as a strong foundation for all HCPs in oncology, given its feasibility, effectiveness, and accessibility through the EL format. However, since participation has been low and, according to the results of **Study 1** of this dissertation, no other thoroughly evaluated and effective communication programs are available, it may be necessary to mandate this training for all HCPs involved in oncology care in Germany on a regular basis. Integrating components of this training into the undergraduate medical program at the UKE is an important first step that has already been initiated. Given the diverse professional backgrounds among HCPs, tailoring the intensity and duration of training for specific groups could enhance their knowledge and skills, as their working realities differ. For instance, psychologists typically have more time and focus primarily on assessing psychological needs, while nurses and physicians, although responsible for these aspects, must also manage a broader range of clinical responsibilities.

5.4. Strengths and limitations of the presented studies

A number of strengths and limitations of this dissertation need to be discussed.

Strengths

First, the sequential mixed methods design facilitated the development and evaluation of an evidence-based intervention (**Study 3**), which was grounded in the results of **Studies 1** and **2** of this dissertation. Integrating the results of the systematic review (**Study 1**), the experiences and views of HCPs (**Study 2**), and the quantitative rigor **of Study 3**, which offered measurable outcomes and robust statistical analyses, strengthens this dissertation by providing comprehensive insights into the various aspects of communication needs, perspectives and skills. This methodological synergy not only enriches the overall findings but also enhances the validity and reliability of the conclusions drawn, ultimately contributing to a more nuanced understanding of how HCPs can better support

parents throughout the cancer journey. Furthermore, all four studies of this dissertation can be aligned within the MRC framework for developing and evaluating complex interventions in implementation research, as illustrated in Figure 4. This alignment facilitates a structured approach that enhances the coherence and relevance of the findings while providing a strong basis for future research and practice. In addition, all four studies were conducted according to good scientific practice and followed specific guidelines to ensure methodological transparency and quality (e.g., **Study 1** (Publication 2) was registered within PROSPERO and followed the PRISMA Guidelines; **Study 2** (Publication 4) follows the guideline Standards for Reporting Qualitative Research [180]; **Study 3** followed the SPIRIT (Publication 1) as well as the CONSORT guidelines (Publication 3)). In addition, **Studies 1**, **3**, and **4** employed established and robust methodologies, enhancing the credibility of the findings. In **Study 1** (Publication 2), an extensive search strategy, as well as two additional updates of the primary search, were applied, making the methodology of the systematic review rigorous and comprehensive. By employing a three-armed pilot-RCT in **Study 3** (Publication 1 and 3) and incorporating an evaluation according to Kirkpatrick's framework [125], this methodological design demonstrates a high level of rigor, which not only enhances the reliability of the findings but also provides a solid foundation for future research. Lastly, a notable strength of this dissertation lies in the methodology of **Study 4** (Publication 5), which applies a thorough translation process that adheres to established guidelines and includes an assessment of face validity through cognitive interviews with various HCPs in oncology. Additionally, an adequate sample size was applied in **Study 3** for the RCT, and in **Study 4** to conduct robust factor analysis and psychometric evaluations, thus contributing further to the overall methodological rigor of this dissertation.

Another strength of this dissertation lies in its systematic and structured approach to developing a complex intervention. Initially, a thorough literature search was conducted in **Study 1** (Publication 2), which provided a solid foundation for understanding the existing knowledge and gaps. This was followed by a needs assessment in **Study 2** (Publication 4), where the qualitative analysis highlighted the importance of considering local needs and organizational contexts, as recommended by Ammentorp et al. [172] These insights were essential in intervention development of **Study 3**, the RCT that represents, to the best of my knowledge, the first targeted intervention designed to enhance HCPs' knowledge and skills specifically related to parental cancer. By thoroughly considering the diverse needs and experiences of HCPs, this intervention ensures relevance and practicality for real-world application, thereby building a well-founded framework for effective communication training in this critical area of healthcare.

Limitations

However, the following **limitations** should be taken into account when interpreting the results of this dissertation. A recurring limitation across this dissertation is the restricted generalizability of the findings due to specific sampling contexts. For instance, the search strategy of **Study 1** (Publication 2) was limited to English and German articles and may not have captured all relevant studies. Furthermore, the sample size of **Study 2** (Publication 4) and **Study 3** (Publication 3) was small and primarily included participants from urban areas like greater Hamburg, making it less representative of broader German conditions. Similarly, the reliance of **Study 4** (Publication 5) relied on a voluntarily participating sample of HCPs from **Study 3**, which further restricts the applicability of results to the wider population and may not accurately reflect the populations being studied. Additionally, the recruitment strategy used in **Study 3** involved snowball sampling, thus introducing biases that impact the overall representativeness of the findings in **Studies 3** and **4**. Further biases necessitated caution in interpreting the results of this dissertation. Self-reported practices were a common method across the **Studies 2**, **3** and **4**. This reliance on self-reporting may lead to biases, such as social desirability bias. Furthermore, volunteer bias may arise from participant selection, with those volunteering potentially differing from non-participants in significant ways, as noted in **Studies 2**, **3** and **4**. Despite the various methodological strengths of this dissertation, there are also some limitations, especially regarding **Studies 3** and **4**. The inclusion of non-psychometrically tested instruments raises concerns about the reliability and validity of measurement tools used throughout **Study 3** (Publication 4) and due to the secondary analysis performed in **Study 4** (Publication 5), assessment of divergent validity was not possible. Lastly, variability in content and measurement tools across studies introduces limitations. **Study 1** (Publication 2) noted significant variability in CST content and assessments, complicating quality evaluations. **Study 4** (Publication 5) highlighted close associations among items, indicating potential issues in factor analysis. Such variability suggests a need for more standardized measures to improve coherence and comparability across CST studies.

5.5. Conclusion

This dissertation made valuable contributions in assessing and addressing HCPs' communication skills within the context of cancer care, particularly when patients are parents of minor children. Through a comprehensive mixed-method design, the results of the four studies of this dissertation emphasize the urgent need for rigorous, evidence-based CSTs that address child- and family-related aspects in cancer care. Future research should focus on refining existing training programs (e.g., EL or blended training including aspects of interprofessional collaboration) and their evaluation

methods (e.g., standardized patient assessments), as well as exploring the perceptions and experiences of HCPs in diverse settings to enhance the quality of care provided to families affected by parental cancer. Within practice, implementing systematic screening practices as well as structures to provide specific information on parenthood and cancer, regardless of age or status of the patient, is necessary to provide high-quality cancer care to all cancer patients parenting minor children. Further research is necessary to validate these preliminary findings and explore the long-term effectiveness of the intervention presented in this dissertation, including contextual factors hindering possible long-term implementation of the intervention, ensuring that all stakeholders in the healthcare system can fully engage in high-quality cancer care for the benefit of families navigating the challenges of parental cancer. Ultimately, improving HCPs' communication competencies - including interprofessional collaboration - is essential for ensuring comprehensive support for families affected by parental cancer.

6. List of abbreviations

CFA	Confirmatory factor analysis
CFI	Comparative Fit Index
CG	Control group
COSMIN	Consensus-based standards for the selection of health measurement instruments
CST	Communication skills training
EL	E-learning
F2F	Face-to-face
HCP	Healthcare professional
MRC	Medical Research Council
SPA	Standardized Patient Assessment
SE-12	Self-Efficacy questionnaire
SE-fam	Self-efficacy questionnaire, assessing child- and family-specific communication skills and related attitudes
RCT	Randomized controlled trial
RMSEA	Root Mean Square Error of Approximation
UKE	University Medical Center Hamburg-Eppendorf

7. List of tables and figures

Tables.

Figures.

8. References

1. Rober Koch Institut, Zentrum für Krebsregisterdaten. *Cancer in Germany 2019/2020*. 2024 [cited 2025 27.01.]; Available from: https://www.krebsdaten.de/Krebs/EN/Content/Cancer_sites/All_cancers/all_cancers_node.html#:~:text=The%20ZfKD%20estimates%20that%20in,or%20the%20lung%20(56%2C700).
2. Mehnert, A., et al., *One in two cancer patients is significantly distressed: Prevalence and indicators of distress.* Psychooncology, 2018. **27**(1): p. 75-82.
3. Bower, J.E., *Cancer-related fatigue--mechanisms, risk factors, and treatments.* Nat Rev Clin Oncol, 2014. **11**(10): p. 597-609.
4. van den Beuken-van Everdingen, M.H., et al., *Prevalence of pain in patients with cancer: a systematic review of the past 40 years.* Ann Oncol, 2007. **18**(9): p. 1437-49.
5. Janelsins, M.C., S.R. Kesler, T.A. Ahles, and G.R. Morrow, *Prevalence, mechanisms, and management of cancer-related cognitive impairment.* Int Rev Psychiatry, 2014. **26**(1): p. 102-13.
6. Bayly, J.L. and M. Lloyd-Williams, *Identifying functional impairment and rehabilitation needs in patients newly diagnosed with inoperable lung cancer: a structured literature review.* Support Care Cancer, 2016. **24**(5): p. 2359-2379.
7. Aaronson, N.K., et al., *Beyond treatment - Psychosocial and behavioural issues in cancer survivorship research and practice.* EJC Suppl, 2014. **12**(1): p. 54-64.
8. Han, W.T., et al., *Breast cancer and problems with medical interactions: relationships with traumatic stress, emotional self-efficacy, and social support.* Psychooncology, 2005. **14**(4): p. 318-30.
9. Roth, A.J., et al., *Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study.* Cancer, 1998. **82**(10): p. 1904-8.
10. Lam, W.W., et al., *The evolution of psychological distress trajectories in women diagnosed with advanced breast cancer: a longitudinal study.* Psychooncology, 2013. **22**(12): p. 2831-9.
11. Berry, D.L., et al., *Self-reported adherence to oral cancer therapy: relationships with symptom distress, depression, and personal characteristics.* Patient Prefer Adherence, 2015. **9**: p. 1587-92.
12. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, D.K., AWMF). *Psychoonkologische Diagnostik, Beratung und Behandlung von erwachsenen Krebspatient*innen, Langversion 2.1*. 2023 [cited 2024 12-12]; Available from: https://www.leitlinienprogramm-onkologie.de/leitlinien/psychoonkologie/.
13. Carlson, L.E. and B.D. Bultz, *Benefits of psychosocial oncology care: improved quality of life and medical cost offset.* Health Qual Life Outcomes, 2003. **1**: p. 8.
14. Bognár, S.A., et al., *Psychological intervention improves quality of life in patients with early-stage cancer: a systematic review and meta-analysis of randomized clinical trials.* Scientific Reports, 2024. **14**(1): p. 13233.
15. care., I.f.p.-a.f.-c. *Patient- and Family-Centered Care*. 2024 [cited 2025 25.01.]; Available from: https://www.ipfcc.org/.
16. Hsu, C., et al., *Actions and processes that patients, family members, and physicians associate with patient- and family-centered care.* BMC Fam Pract, 2019. **20**(1): p. 35.
17. Clay, A.M. and B. Parsh, *Patient- and Family-Centered Care: It's Not Just for Pediatrics Anymore.* AMA J Ethics, 2016. **18**(1): p. 40-4.
18. Inhestern, L., et al., *Estimates of Prevalence Rates of Cancer Patients With Children and Well-Being in Affected Children: A Systematic Review on Population-Based Findings.* Front Psychiatry, 2021. **12**: p. 765314.

19. Sung, H., et al., *Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries.* CA Cancer J Clin, 2021. **71**(3): p. 209-249.
20. Rossi, L., C. Mazzara, and O. Pagani, *Diagnosis and Treatment of Breast Cancer in Young Women.* Curr Treat Options Oncol, 2019. **20**(12): p. 86.
21. Ernst, J.C., et al., *[Psychosocial care of children with a parent having cancer--an appraisal of specific care services in Germany].* Psychother Psychosom Med Psychol, 2011. **61**(9-10): p. 426-34.
22. Buchbinder, M., J. Longhofer, and K. McCue, *Family routines and rituals when a parent has cancer.* Fam Syst Health, 2009. **27**(3): p. 213-27.
23. Kim, Y., F. Baker, R.L. Spillers, and D.K. Wellisch, *Psychological adjustment of cancer caregivers with multiple roles.* Psychooncology, 2006. **15**(9): p. 795-804.
24. Northouse, L.L., et al., *Living with prostate cancer: patients' and spouses' psychosocial status and quality of life.* J Clin Oncol, 2007. **25**(27): p. 4171-7.
25. Semple, C.J. and E. McCaughan, *Family life when a parent is diagnosed with cancer: impact of a psychosocial intervention for young children.* Eur J Cancer Care (Engl), 2013. **22**(2): p. 219-31.
26. Schiena, E., et al., *An Exploratory Needs Analysis of Parents Diagnosed with Cancer.* Australian Social Work, 2019. **72**(3): p. 325-335.
27. Nilsson, M.E., et al., *Mental health, treatment preferences, advance care planning, location, and quality of death in advanced cancer patients with dependent children.* Cancer, 2009. **115**(2): p. 399-409.
28. Johannsen, L., et al., *The impact of cancer on the mental health of patients parenting minor children: A systematic review of quantitative evidence.* Psychooncology, 2022. **31**(6): p. 869-878.
29. Muriel, A.C., et al., *Measuring psychosocial distress and parenting concerns among adults with cancer: the Parenting Concerns Questionnaire.* Cancer, 2012. **118**(22): p. 5671-8.
30. Park, E.M., et al., *Parenting while living with advanced cancer: A qualitative study.* Palliat Med, 2017. **31**(3): p. 231-238.
31. Romare Strandh, M., et al., *The Complexity of Being a Parent in the Hospital and a Patient at Home: A Qualitative Study on Parenting Concerns and Challenges Among Parents With Cancer.* Cancer Nurs, 2025. **48**(1): p. E9-e17.
32. Li, J.L., Q. Ye, and N. Liu, *Cancer parents' experiences of parenting concerns about minor children: A meta-synthesis of qualitative studies.* Int J Nurs Stud Adv, 2024. **6**: p. 100210.
33. Kuswanto, C.N., L. Stafford, J. Sharp, and P. Schofield, *Psychological distress, role, and identity changes in mothers following a diagnosis of cancer: A systematic review.* Psychooncology, 2018. **27**(12): p. 2700-2708.
34. Konings, S., F.E.J. McDonald, and P. Patterson, *Supporting parents impacted by cancer: Development of an informational booklet for parents with cancer who have adolescent and young adult children.* Psychooncology, 2020. **29**(12): p. 2101-2104.
35. Dalton, L., et al., *Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent.* Lancet, 2019. **393**(10176): p. 1164-1176.
36. Dencker, A., et al., *Disrupted biographies and balancing identities: A qualitative study of cancer patients' communication with healthcare professionals about dependent children.* Eur J Cancer Care (Engl), 2019. **28**(2): p. e12991.
37. Moore, C.W., et al., *Parenting changes in adults with cancer.* Cancer, 2015. **121**(19): p. 3551-7.
38. Stiffler, D., J. Haase, B. Hosei, and B. Barada, *Parenting experiences with adolescent daughters when mothers have breast cancer.* Oncol Nurs Forum, 2008. **35**(1): p. 113-20.
39. Check, D.K., et al., *Concerns underlying treatment preferences of advanced cancer patients with children.* Psychooncology, 2017. **26**(10): p. 1491-1497.

40. Li, Z.H.J., et al., *Evaluating the childcare needs of cancer patients undergoing radiation therapy.* Support Care Cancer, 2023. **31**(8): p. 463.
41. Fearnley, R. and J.W. Boland, *Parental Life-Limiting Illness: What Do We Tell the Children?* Healthcare (Basel), 2019. **7**(1).
42. Chen, R., et al., *Impact of parental cancer on IQ, stress resilience, and physical fitness in young men.* Clin Epidemiol, 2018. **10**: p. 593-604.
43. Romer, G., *Kinder körperlich kranker Eltern: Psychische Belastungen, Wege der Bewältigung und Perspektiven der seelischen Gesundheitsvorsorge.* Praxis der Kinderpsychologie und Kinderpsychatrie 2007. **56**(10): p. 20.
44. Hauken, M.A., M. Senneseth, A. Dyregrov, and K. Dyregrov, *Anxiety and the Quality of Life of Children Living With Parental Cancer.* Cancer Nurs, 2018. **41**(1): p. E19-e27.
45. Zheng, Z., et al., *Associations of Parental Cancer With School Absenteeism, Medical Care Unaffordability, Health Care Use, and Mental Health Among Children.* JAMA Pediatr, 2022. **176**(6): p. 593-601.
46. Morris, J.N., A. Martini, and D. Preen, *The well-being of children impacted by a parent with cancer: an integrative review.* Support Care Cancer, 2016. **24**(7): p. 3235-51.
47. Forrest, G., C. Plumb, S. Ziebland, and A. Stein, *Breast cancer in the family--children's perceptions of their mother's cancer and its initial treatment: qualitative study.* Bmj, 2006. **332**(7548): p. 998-1003.
48. Visser, A., et al., *The impact of parental cancer on children and the family: a review of the literature.* Cancer Treat Rev, 2004. **30**(8): p. 683-94.
49. Jim, H.S. and P.B. Jacobsen, *Posttraumatic stress and posttraumatic growth in cancer survivorship: a review.* Cancer J, 2008. **14**(6): p. 414-9.
50. Osborn, T., *The psychosocial impact of parental cancer on children and adolescents: a systematic review.* Psychooncology, 2007. **16**(2): p. 101-26.
51. Watson, M., et al., *Factors associated with emotional and behavioural problems among school age children of breast cancer patients.* Br J Cancer, 2006. **94**(1): p. 43-50.
52. Schliemann, A., et al., *Reduced Psychosocial Well-Being among the Children of Women with Early-Onset Breast Cancer.* Curr Oncol, 2023. **30**(12): p. 10057-10074.
53. Möller, B., et al., *Children of cancer patients: prevalence and predictors of emotional and behavioral problems.* Cancer, 2014. **120**(15): p. 2361-70.
54. Sigal, J.J., et al., *Maternal preoccupation and parenting as predictors of emotional and behavioral problems in children of women with breast cancer.* J Clin Oncol, 2003. **21**(6): p. 1155-60.
55. Steck, B., et al., *Mental health problems in children of somatically ill parents, e.g. multiple sclerosis.* Eur Child Adolesc Psychiatry, 2007. **16**(3): p. 199-207.
56. Krattenmacher, T., et al., *Parental cancer: factors associated with children's psychosocial adjustment--a systematic review.* J Psychosom Res, 2012. **72**(5): p. 344-56.
57. Inhestern, L., A.C. Haller, O. Wlodarczyk, and C. Bergelt, *Psychosocial Interventions for Families with Parental Cancer and Barriers and Facilitators to Implementation and Use - A Systematic Review.* PLoS One, 2016. **11**(6): p. e0156967.
58. Lewis, F.M., et al., *The Enhancing Connections Program: a six-state randomized clinical trial of a cancer parenting program.* J Consult Clin Psychol, 2015. **83**(1): p. 12-23.
59. Bugge, K.E., S. Helseth, and P. Darbyshire, *Children's experiences of participation in a family support program when their parent has incurable cancer.* Cancer Nurs, 2008. **31**(6): p. 426-34.
60. Tucker, A.R., D. Sugerman, and R. Zelov, *On Belay:Providing Connection, Support, and Empowerment to Children Who Have a Parent With Cancer.* Journal of Experiential Education, 2013. **36**(2): p. 93-105.

61. Niemelä, M., H. Hakko, and S. Räsänen, *A systematic narrative review of the studies on structured child-centred interventions for families with a parent with cancer.* Psychooncology, 2010. **19**(5): p. 451-61.
62. Geertz, W., W. Frerichs, L. Inhestern, and C. Bergelt, *Supportive and psychosocial peer-group interventions for children and adolescents of parents with cancer: a systematic review.* Patient Education and Counseling, 2023: p. 107844.
63. Heynemann, S., J. Philip, and S.-A. McLachlan, *An exploration of the perceptions, experience and practice of cancer clinicians in caring for patients with cancer who are also parents of dependent-age children.* Supportive Care in Cancer, 2021. **29**(7): p. 3895-3902.
64. Heier, L., et al., *Communication patterns in families affected by parental cancer from the healthy parents' perspective-process evaluation of the complex intervention Family-SCOUT.* Support Care Cancer, 2024. **32**(8): p. 500.
65. Fearnley, R. and J.W. Boland, *Communication and support from health-care professionals to families, with dependent children, following the diagnosis of parental life-limiting illness: A systematic review.* Palliat Med, 2017. **31**(3): p. 212-222.
66. Perak, K., et al., *Family adjustment and resilience after a parental cancer diagnosis.* Supportive Care in Cancer, 2024. **32**(7): p. 409.
67. Shands, M.E. and F.M. Lewis, *Parents With Advanced Cancer: Worries About Their Children's Unspoken Concerns.* Am J Hosp Palliat Care, 2021. **38**(8): p. 920-926.
68. Kleinhaus, H., E. Brähler, G. Romer, and J. Ernst, *Kommunikation über die elterliche Krebserkrankung mit minderjährigen Kindern: Notwendigkeit, Belastung und Themen aus Elternsicht.* Psychother Psychosom Med Psychol, 2022. **73**(02): p. 85-88.
69. Huizinga, G.A., et al., *The quality of communication between parents and adolescent children in the case of parental cancer.* Annals of Oncology, 2005. **16**(12): p. 1956-1961.
70. Hammersen, F., et al., *Psychosocial and family-centered support among breast cancer patients with dependent children.* Psychooncology, 2021. **30**(3): p. 361-368.
71. Ernst, J.C., et al., *Use and need for psychosocial support in cancer patients.* Cancer, 2013. **119**(12): p. 2333-2341.
72. Inhestern, L., L.M. Johannsen, and C. Bergelt, *Families Affected by Parental Cancer: Quality of Life, Impact on Children and Psychosocial Care Needs.* Frontiers in Psychiatry, 2021. **12**.
73. Inhestern, L., W. Frerichs, L.M. Johannsen, and C. Bergelt, *Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot study.* BMJ Open, 2019. **9**(10): p. e032778.
74. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, D.K., AWMF). *S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.4, 2021, AWMF Registernummer: 032-045OL*. 2021 [cited 2024 12-12]; Available from: http://www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom/.
75. Bundesministerium für Gesundheit. *Psychoonkologische Versorgung in Deutschland: Bundesweite Bestandsaufnahme und Analyse - Wissenschaftliches Gutachten im Auftrag des Bundesministeriums für Gesundheit*. 2018 [cited 2024 12-22]; Available from: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiXx8jX9LGLAxUhVPEDHRtcBBQQFnoECBEQAQ&url=https%3A%2F%2Fwww.bundesgesundheitsministerium.de%2Ffileadmin%2FDateien%2F5_Publikationen%2FGesundheit%2FBerichte%2FPsoViD_Gutachten_BMG_19_02_14_gender.pdf&usg=AOvVaw0vnjIx8lmG15vjBf1kQJL7&opi=89978449.
76. Lehman, B.J., D.M. David, and J.A. Gruber, *Rethinking the biopsychosocial model of health: Understanding health as a dynamic system.* Social and Personality Psychology Compass, 2017. **11**(8): p. e12328.

77. Hahlweg, P., et al., *Moving towards patient-centered care and shared decision-making in Germany.* Z Evid Fortbild Qual Gesundhwes, 2022. **171**: p. 49-57.
78. Santana, M.J., et al., *How to practice person-centred care: A conceptual framework.* Health Expect, 2018. **21**(2): p. 429-440.
79. Christalle, E., et al., *Assessment of patient centredness through patient-reported experience measures (ASPIRED): protocol of a mixed-methods study.* BMJ Open, 2018. **8**(10): p. e025896.
80. Epstein, R.M., et al., *Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues.* Soc Sci Med, 2005. **61**(7): p. 1516-28.
81. Gustavsson, K., et al., *Healthcare professionals' experiences of job satisfaction when providing person-centred care: a systematic review of qualitative studies.* BMJ Open, 2023. **13**(6): p. e071178.
82. Institute of Medicine Committee on Quality of Health Care in, A., *Crossing the Quality Chasm: A New Health System for The 21st Century*. BMJ. 2001.
83. Ekman, I., *Practising the ethics of person-centred care balancing ethical conviction and moral obligations.* Nurs Philos, 2022. **23**(3): p. e12382.
84. Ekman, I., et al., *Person-centered care--ready for prime time.* Eur J Cardiovasc Nurs, 2011. **10**(4): p. 248-51.
85. Scholl, I., J.M. Zill, M. Härter, and J. Dirmaier, *An Integrative Model of Patient-Centeredness – A Systematic Review and Concept Analysis.* PLOS ONE, 2014. **9**(9): p. e107828.
86. Gilligan, C., et al., *Assessment of communication skills in health professions education; Ottawa 2024 consensus statement.* Med Teach, 2024. **46**(12): p. 1593-1606.
87. Deveugele, M., *Communication training: Skills and beyond.* Patient Educ Couns, 2015. **98**(10): p. 1287-91.
88. Gattellari, M., P.N. Butow, and M.H. Tattersall, *Sharing decisions in cancer care.* Soc Sci Med, 2001. **52**(12): p. 1865-78.
89. Street, R.L., Jr., *How clinician-patient communication contributes to health improvement: modeling pathways from talk to outcome.* Patient Educ Couns, 2013. **92**(3): p. 286-91.
90. Epstein, R.M., K. Fiscella, C.S. Lesser, and K.C. Stange, *Why the nation needs a policy push on patient-centered health care.* Health Aff (Millwood), 2010. **29**(8): p. 1489-95.
91. van Diepen, C., A. Fors, I. Ekman, and G. Hensing, *Association between person-centred care and healthcare providers' job satisfaction and work-related health: a scoping review.* BMJ Open, 2020. **10**(12): p. e042658.
92. Burgener, A.M., *Enhancing Communication to Improve Patient Safety and to Increase Patient Satisfaction.* Health Care Manag (Frederick), 2017. **36**(3): p. 238-243.
93. Johannsen, L.M., et al., *Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study.* Psychooncology, 2023. **32**(10): p. 1567-1577.
94. Dencker, A., B.A. Rix, P. Boge, and T. Tjornhoj-Thomsen, *A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children.* Psychooncology, 2017(12): p. 2162-2167.
95. Semple, C.J. and T. McCance, *Experience of parents with head and neck cancer who are caring for young children.* J Adv Nurs, 2010. **66**(6): p. 1280-90.
96. Johannsen, L., W. Frerichs, L. Inhestern, and C. Bergelt, *Exploring the perspectives of cancer patients parenting minor children: A qualitative study on family-centered cancer care experiences.* Patient Education and Counseling, 2023. **117**: p. 107989.
97. Melchiors, L., W. Geertz, and L. Inhestern, *Parental Cancer: Acceptance and Usability of an Information Booklet for Affected Parents.* Frontiers in Psychology, 2022. **13**.

98. Weeks, N., et al., *A summary of high quality online information resources for parents with cancer who have adolescent and young adult children: A scoping review.* Psychooncology, 2019. **28**(12): p. 2323-2335.
99. Thomson, M.D., M.W. Genderson, and L.A. Siminoff, *Understanding cancer caregiver burden over time: Dyadic assessments of family cohesion, conflict and communication.* Patient Education and Counseling, 2022. **105**(6): p. 1545-1551.
100. Husson, O., F. Mols, and L.V. van de Poll-Franse, *The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review.* Ann Oncol, 2011. **22**(4): p. 761-772.
101. Fallowfield, L. and V. Jenkins, *Communicating sad, bad, and difficult news in medicine.* Lancet, 2004. **363**(9405): p. 312-9.
102. Schouten, B., J. Bergs, P. Vankrunkelsven, and J. Hellings, *Healthcare professionals' perspectives on the prevalence, barriers and management of psychosocial issues in cancer care: A mixed methods study.* Eur J Cancer Care (Engl), 2019. **28**(1): p. e12936.
103. Barnes, J., et al., *Qualitative interview study of communication between parents and children about maternal breast cancer.* Bmj, 2000. **321**(7259): p. 479-82.
104. Turner, J., *Children's and family needs of young women with advanced breast cancer: A review.* Palliative and Supportive Care, 2004. **2**(1): p. 55-64.
105. Turner, J., et al., *Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention.* European Journal of Cancer, 2009. **45**(10): p. 1798-1806.
106. Sinclair, M., et al., *Maternal breast cancer and communicating with children: A qualitative exploration of what resources mothers want and what health professionals provide.* Eur J Cancer Care (Engl), 2019. **28**(6): p. e13153.
107. Hanna, J.R., E. McCaughan, E.R. Beck, and C.J. Semple, *Providing care to parents dying from cancer with dependent children: Health and social care professionals' experience.* Psychooncology, 2021. **30**(3): p. 331-339.
108. Golsäter, M., M. Henricson, K. Enskär, and S. Knutsson, *Are children as relatives our responsibility? - How nurses perceive their role in caring for children as relatives of seriously ill patients.* Eur J Oncol Nurs, 2016. **25**: p. 33-39.
109. O'Neill, C., et al., *Adapting and testing an eLearning resource for professionals to support families when a significant caregiver for children is dying with cancer.* BMC Palliative Care, 2024. **23**(1): p. 268.
110. Uitterhoeve, R.J., et al., *The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature.* Eur J Cancer Care (Engl), 2010. **19**(4): p. 442-57.
111. Moore, P.M., et al., *Communication skills training for healthcare professionals working with people who have cancer.* Cochrane Database Syst Rev, 2018. **7**(7): p. Cd003751.
112. Skrabal Ross, X., et al., *Piloting a new cross-sector model of care to support parents with cancer: feasibility and acceptability of the Parent Support Worker role.* Supportive Care in Cancer, 2024. **32**(7): p. 435.
113. Barth, J. and P. Lannen, *Efficacy of communication skills training courses in oncology: a systematic review and meta-analysis.* Ann Oncol, 2011. **22**(5): p. 1030-1040.
114. Berg, M.N., et al., *Effectiveness of online communication skills training for cancer and palliative care health professionals: A systematic review.* Psychooncology, 2021. **30**(9): p. 1405-1419.
115. Bos – van den Hoek, D.W., et al., *Communication skills training for healthcare professionals in oncology over the past decade: a systematic review of reviews.* Current Opinion in Supportive and Palliative Care, 2019. **13**(1).

116. McCormack, L.A., et al., *Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach.* Social Science & Medicine, 2011. **72**(7): p. 1085-1095.
117. Mata, Á.N.d.S., et al., *Training in communication skills for self-efficacy of health professionals: a systematic review.* Human Resources for Health, 2021. **19**(1): p. 30.
118. Christalle, E., et al., *Development and content validity of the Experienced Patient-Centeredness Questionnaire (EPAT)—A best practice example for generating patient-reported measures from qualitative data.* Health Expectations, 2022. **25**(4): p. 1529-1538.
119. Skivington, K., et al., *A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance.* BMJ, 2021. **374**: p. n2061.
120. Nørgaard, B., et al., *Health care professionals' experience of participating in a communication course in an orthopaedic department.* International Journal of Orthopaedic and Trauma Nursing, 2011. **15**(4): p. 202-211.
121. Møller, J.E., et al., *Transfer of communication teaching skills from university to the clinical workplace – does it happen? A mixed methods study.* BMC Medical Education, 2021. **21**(1): p. 433.
122. Creswell, J.W., *A Concise Introduction to Mixed Methods Research*. 2014: SAGE Publications.
123. Innovationsausschuss, G-BA. *KOMKEK – Entwicklung eines Trainings für Behandler von Krebspatienten zur Stärkung der Kompetenz im Umgang mit krebskranken Eltern minderjähriger Kinder*. 2023 [cited 2025 02-02]; Available from: https://innovationsfonds.g-ba.de/beschluesse/komkek.175.
124. Craig, P., et al., *Developing and evaluating complex interventions: the new Medical Research Council guidance.* BMJ, 2008. **337**: p. a1655.
125. Kirkpatrick, D. and J. Kirkpatrick, *Evaluating Training Programs: The Four Levels*. 2006: Berrett-Koehler Publishers.
126. Harkness, J., B.E. Pennell, and A. Schoua-Glusberg, *Survey questionnaire translation and assessment.* Methods for testing and evaluating survey questionnaires, 2004: p. 453-473.
127. Prüfer, P. and M. Rexroth. *Kognitive Interviews.* How-to-Reihe, Nr. 15. 2005 [cited 2020 27.12.2020]; Available from: https://www.gesis.org/fileadmin/upload/forschung/publikationen/gesis_reihen/hohow/How_to15PP_MR.pdf.
128. Page, M.J., et al., *The PRISMA 2020 statement: an updated guideline for reporting systematic reviews.* Bmj, 2021. **372**: p. n71.
129. NIH. *Quality Assessment Tool for Before-After Studies with No Control Group.* . 2014 [cited 2021; Available from: https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools.
130. Kuckartz, U., *Qualitative Inhaltsanalyse. Methoden, Praxis, Computerunterstützung*. 4th ed. 2018, Weinheim, Basel: Beltz Juventa.
131. Johannsen, L.M., W. Frerichs, L. Inhestern, and C. Bergelt, *Assessing competencies of healthcare professionals caring for parents with cancer: The development of an innovative assessment tool.* Psycho-Oncology, 2020. **29**(10): p. 1670-1677.
132. Axboe, M.K., K.S. Christensen, P.E. Kofoed, and J. Ammentorp, *Development and validation of a self-efficacy questionnaire (SE-12) measuring the clinical communication skills of health care professionals.* BMC Med Educ, 2016. **16**(1): p. 272.
133. Harkness, J.A., A. Villar, and B. Edwards, *Translation, adaptation, and design*, in *Survey methods in multinational, multiregional, and multicultural contexts.* 2010, John Wiley & Sons, Inc.: Hoboken, NJ, US. p. 117-140.
134. Terwee, C.B., et al., *COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study.* Qual Life Res, 2018. **27**(5): p. 1159-1170.

135. de Vet, H., C. Terwee, L. Mokkink, and D. Knol, *Development of a measurement instrument*, in *Measurement in Medicine: A Practical Guide*, H.C.W. de Vet, C.B. Terwee, L.B. Mokkink, and D.L. Knol, Editors. 2011, Cambridge University Press: Cambridge. p. 30-64.
136. Hvidt, E.A., et al., *Developing and evaluating a course programme to enhance existential communication with cancer patients in general practice.* Scandinavian journal of primary health care, 2018. **36**(2): p. 142-151.
137. Trockel, M., et al., *A Brief Instrument to Assess Both Burnout and Professional Fulfillment in Physicians: Reliability and Validity, Including Correlation with Self-Reported Medical Errors, in a Sample of Resident and Practicing Physicians.*
138. Ammentorp, J., et al., *Mandatory communication training of all employees with patient contact.* Patient Educ Couns, 2014. **95**(3): p. 429-32.
139. Epstein, R.M., et al., *Effect of a Patient-Centered Communication Intervention on Oncologist-Patient Communication, Quality of Life, and Health Care Utilization in Advanced Cancer: The VOICE Randomized Clinical Trial.* JAMA Oncol, 2017. **3**(1): p. 92-100.
140. Harnischfeger, N., et al., *Effects of a communication training for oncologists on early addressing palliative and end-of-life care in advanced cancer care (PALLI-COM): a randomized, controlled trial.* ESMO Open, 2022. **7**(6): p. 100623.
141. Felber, S.J., et al., *Talking about dying and death: Essentials of communicating about approaching death from the perspective of major stakeholders.* Palliative and Supportive Care, 2024. **22**(5): p. 1199-1208.
142. Tulsky, J.A., et al., *A Research Agenda for Communication Between Health Care Professionals and Patients Living With Serious Illness.* JAMA Internal Medicine, 2017. **177**(9): p. 1361-1366.
143. Hashim, M.J., *Patient-Centered Communication: Basic Skills.* Am Fam Physician, 2017. **95**(1): p. 29-34.
144. Steffensen, K.D., *The promise of shared decision making in healthcare.* AMS Review, 2019. **9**(1): p. 105-109.
145. Dilworth, S., et al., *Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: a systematic review.* Psychooncology, 2014. **23**(6): p. 601-12.
146. Banerjee, S.C., et al., *The implementation and evaluation of a communication skills training program for oncology nurses.* Transl Behav Med, 2017. **7**(3): p. 615-623.
147. Cannity, K.M., et al., *Acceptability and efficacy of a communication skills training for nursing students: Building empathy and discussing complex situations.* Nurse Educ Pract, 2021. **50**: p. 102928.
148. Fuoto, A. and K.M. Turner, *Palliative Care Nursing Communication: An Evaluation of the COMFORT Model.* Journal of Hospice & Palliative Nursing, 2019. **21**(2): p. 124-130.
149. Wittenberg, E., J.V. Goldsmith, and A. Lee, *Caring for family caregivers: a pilot test of an online COMFORT™ SM communication training module for undergraduate nursing students.* Journal of Cancer Education, 2020. **35**(1): p. 138-143.
150. Cronin, J.A. and S. Finn, *Implementing and Evaluating the COMFORT Communication in Palliative Care Curriculum for Oncology Nurses.* Journal of Hospice & Palliative Nursing, 2017. **19**(2): p. 140-146.
151. Quinn, K., P. Hudson, M. Ashby, and K. Thomas, *"Palliative care: the essentials": evaluation of a multidisciplinary education program.* J Palliat Med, 2008. **11**(8): p. 1122-9.
152. Semple, C., E. McCaughan, and R. Smith, *How education on managing parental cancer can improve family communication.* Cancer Nursing Practice, 2017. **16**(5): p. 34-40.
153. Sivesind, D., et al., *Communicating with patients in cancer care; what areas do nurses find most challenging?* J Cancer Educ, 2003. **18**(4): p. 202-9.

154. Turner, J., et al., *Oncology nurses' perceptions of their supportive care for parents with advanced cancer: challenges and educational needs.* Psychooncology, 2007. **16**(2): p. 149-57.
155. Chen, C.S., et al., *Nurses' Perceptions of Psychosocial Care and Barriers to Its Provision: A Qualitative Study.* J Nurs Res, 2017. **25**(6): p. 411-418.
156. Fernández-Basanta, S., L. Lois-Sandá, and M.-J. Movilla-Fernández, *The link between task-focused care and care beyond technique: A meta-ethnography about the emotional labour in nursing care.* Journal of Clinical Nursing, 2023. **32**(13-14): p. 3130-3143.
157. Kissane, D.W., et al., *Communication skills training for oncology professionals.* J Clin Oncol, 2012. **30**(11): p. 1242-7.
158. Collaborative, I.E., *IPEC core competencies for interprofessional collaborative practice: Version 3.* Interprofessional Education Collaborative, 2023.
159. Towers, R., *Providing psychological support for patients with cancer.* Nurs Stand, 2007. **22**(12): p. 50-7; quiz 58.
160. Arber, A. and A. Odelius, *Experiences of Oncology and Palliative Care Nurses When Supporting Parents Who Have Cancer and Dependent Children.* Cancer Nurs, 2018. **41**(3): p. 248-254.
161. Wilcha, R.-J., *Effectiveness of Virtual Medical Teaching During the COVID-19 Crisis: Systematic Review.* JMIR Med Educ, 2020. **6**(2): p. e20963.
162. Shehata, M.H., et al., *Medical Education Adaptations Post COVID-19: An Egyptian Reflection.* J Med Educ Curric Dev, 2020. **7**: p. 2382120520951819.
163. Hensley, A., et al., *A Multicenter Study of Student Engagement and Satisfaction in Online Programs.* J Nurs Educ, 2021. **60**(5): p. 259-264.
164. Eklund, M. and P. Isotalus, *Having it both ways: learning communication skills in face-to-face and online environments.* Frontiers in Education, 2024. **9**.
165. Lipkin, M., *3The history of communication skills knowledge and training*, in *Handbook of Communication in Oncology and Palliative Care*, D. Kissane, B. Bultz, P. Butow, and I. Finlay, Editors. 2010, Oxford University Press. p. 0.
166. Winterburn, S. and S. Wilkinson, *425The challenges and rewards of communication skills training for oncology and palliative care nurses in the United Kingdom*, in *Handbook of Communication in Oncology and Palliative Care*, D. Kissane, B. Bultz, P. Butow, and I. Finlay, Editors. 2010, Oxford University Press. p. 0.
167. Streiner, D.L., G.R. Norman, and J. Cairney, *Health Measurement Scales: A practical guide to their development and use*. 2014: Oxford University Press.
168. Boateng, G.O., et al., *Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer.* Frontiers in Public Health, 2018. **6**.
169. Escribano, S., et al., *Psychometric properties of the Attitudes towards Medical Communication Scale in nursing students.* PeerJ, 2021. **9**: p. e11034.
170. Lindig, A., et al., *Evaluation of a patient-centered communication skills training for nurses (KOMPAT): study protocol of a randomized controlled trial.* BMC Nurs, 2024. **23**(1): p. 2.
171. KK, A., et al., *Effects of on-site Supportive Communication Training (On-site SCT) on doctor-patient communication in oncology: Study protocol of a randomized, controlled mixed-methods trial.* BMC Medical Education, 2024. **24**(1): p. 522.
172. Ammentorp, J., M. Chiswell, and P. Martin, *Translating knowledge into practice for communication skills training for health care professionals.* Patient Education and Counseling, 2022. **105**(11): p. 3334-3338.
173. Delvaux, N., et al., *Physicians' communication with a cancer patient and a relative: a randomized study assessing the efficacy of consolidation workshops.* Cancer, 2005. **103**(11): p. 2397-411.

174. Kwame, A. and P.M. Petrucka, *A literature-based study of patient-centered care and communication in nurse-patient interactions: barriers, facilitators, and the way forward.* BMC Nursing, 2021. **20**(1): p. 158.
175. Frerichs, W., et al., *Child- and family-specific communication skills trainings for healthcare professionals caring for families with parental cancer: A systematic review.* PLoS One, 2022. **17**(11): p. e0277225.
176. Riley, A.H., et al., *Vignettes as research tools in global health communication: a systematic review of the literature from 2000 to 2020.* Journal of Communication in Healthcare, 2021. **14**: p. 283 - 292.
177. Damschroder, L.J., C.M. Reardon, M.A.O. Widerquist, and J. Lowery, *The updated Consolidated Framework for Implementation Research based on user feedback.* Implementation Science, 2022. **17**(1): p. 75.
178. Krebsinformationsdienst, D. *Kinder krebskranker Eltern unterstützen - Wo finden Betroffene Hilfe?* 2022 [cited 2025 2-2]; Available from: https://www.krebsinformationsdienst.de/fachkreise/nachrichten/detail/kinder-krebskranker-eltern-unterstuetzen.
179. Interessensgruppe Kinder krebskranker Eltern (IG KkE). *Verzeichnis bundesweiter Einrichtungen und Angebote für Kinder krebskranker Eltern und deren Familien/Bezugspersonen*. 2022 [cited 2025 2-2]; Available from: https://kinder-krebskranker-eltern.de/wp-content/uploads/2022/11/Verzeichnis-bundesweiter-Angebote-fuer-Kinder-krebskranker-Eltern-IG-KkE-Stand-18.11.22-1-2.pdf.
180. O'Brien, B.C., et al., *Standards for reporting qualitative research: a synthesis of recommendations.* Acad Med, 2014. **89**(9): p. 1245-51.

9. Summary

When a parent is diagnosed with cancer, the entire family is impacted. Minor children experience profound changes in their daily lives, as their parents are less physically and emotionally available. Parents with cancer often feel uncertain about their parenting competence and struggle with how to discuss their illness with their children. Healthcare professionals play a central role by recognizing and addressing the psychosocial burdens faced by these parents. However, a lack of routines, insufficient knowledge, and communication skills can lead to uncertainties, resulting in avoidance of the topic. In Germany, little is known so far about how child- and family-related aspects of care are considered in the communication practices of healthcare providers when a parent has cancer. Additionally, there is a lack of comprehensive, needs-oriented training specifically addressing the topic of parenthood and cancer.

The aim of this dissertation is to address this gap through the following **four studies** and their individual aims across five distinctive publications using a mixed-methods approach: **(1)** to identify what scientifically evaluated communication trainings exist for oncological practitioners that integrate the topic of parental cancer; **(2)** to explore the experiences of healthcare professionals when communicating about child- and family-related aspects in routine cancer care and their opinion about the significance of this topic; **(3)** to develop a needs-oriented training program on the topic of "cancer and parenthood" and evaluate its feasibility and effectiveness within a randomized controlled pilot-study; **(4)** to develop an instrument measuring healthcare professionals' self-efficacy in their communication competencies and assessing its psychometric properties.

To achieve the first sub-objective, a systematic literature review was conducted in **Study 1** (Publication 2) to a) investigate which scientifically evaluated interventions (e.g., training programs on communication) exist for healthcare professionals working in cancer care that incorporate specific modules addressing child- and family-related aspects of care when a parent is diagnosed with cancer, and b) assess the effectiveness of these interventions. Among the nine studies included in this review, only two interventions were specifically designed to enhance the communication of healthcare professionals when a cancer patient is parenting minor children. The remaining seven included only a brief family module, with the specific content remaining unclear. Eight studies showed at least one statistically significant improvement in communication after the intervention, and the quality of all studies was fair.

In **Study 2**, semi-structured interviews were conducted with N=20 healthcare professionals (including doctors, nurses, psychologists) in oncology to achieve the second sub-objective (Publication 4). Participants reported on their experiences and assessments concerning

communication about child- and family-related aspects in routine cancer care. The communication experiences of these professionals revealed considerable variation, influenced by factors such as diagnosis, structural challenges, individual characteristics of the patient and the professional, and the healthcare professional group. Assessments of the relevance of this topic ranged from low priority to high significance, particularly in palliative cases.

For **Study 3**, a study protocol was developed first (Publication 1), followed by the development of a three-hour training program in both in-person and e-learning formats based on the literature review and interviews. This program was then evaluated for feasibility and effectiveness in a randomized controlled pilot-study with a waiting control group involving 152 oncological healthcare professionals (Publication 3). Using linear mixed models, both intervention groups demonstrated a significant increase in knowledge and a greater increase in their self-efficacy related to specific communication skills, while no significant differences in satisfaction between in-person and e-learning training were observed.

Since a suitable questionnaire for measuring the communicative competencies of healthcare professionals was lacking in the German language, in **Study 4**, a German version of the Self-Efficacy Questionnaire (SE-12), the SE-12-G was developed and psychometrically evaluated (Publication 5) to achieve the fourth sub-objective. This involved translating the SE-12 into German, adapting it to the context, adding another scale, and validating it through cognitive interviews. The outcome is a content-valid, comprehensible questionnaire that measures the subjectively perceived communicative competencies of healthcare professionals through two subscales and shows good psychometric properties.

This dissertation demonstrates that basic training for healthcare professionals in oncology regarding child- and parent-related aspects in cancer care is necessary, but has been lacking so far. Within the context of this dissertation developed and needs-oriented intervention aimed to enhance the knowledge and communication skills of healthcare professionals in oncology regarding cancer patients parenting minor children. The comprehensive evaluation of the pilot-study shows that this intervention is both feasible and effective in promoting knowledge and communication skills. However, additional studies are necessary to confirm these findings.

10. Zusammenfassung

Wenn ein Elternteil an Krebs erkrankt, betrifft dies die gesamte Familie. Minderjährige Kinder erleben tiefgreifende Veränderungen im Alltag, da die Eltern physisch und emotional weniger verfügbar sind. Krebskranke Eltern sind oft verunsichert in ihrer elterlichen Kompetenz und wissen nicht, wie sie mit ihren Kindern über die Erkrankung sprechen sollen. Behandelnde Fachkräfte spielen eine zentrale Rolle, indem sie die psychosozialen Belastungen der Eltern erkennen und darauf eingehen. Doch fehlende Routinen, mangelndes Wissen sowie Kommunikationsfähigkeiten können zu Unsicherheiten und damit zur Vermeidung des Themas führen. In Deutschland ist bislang wenig darüber bekannt, wie Elternschaft und Krebs in der Kommunikation von Behandelnden berücksichtigt werden. Zudem fehlt eine umfassende, bedarfsgerechte Fortbildung, die gezielt auf das Thema Elternschaft und Krebs eingeht.

Die vorliegende Dissertation hat das Ziel, diese Lücke durch die folgenden **vier Studien** mit ihren jeweiligen vier Teilzielen zu schließen, die in fünf distinktiven Publikationen präsentiert werden und einen Mixed-Methods Ansatz verfolgen: **(1)** die Identifizierung von wissenschaftlich evaluierten Kommunikationstrainings für onkologisch Behandelnde, die das Thema „Krebserkrankung und Elternschaft“ integrieren; **(2)** die explorative Untersuchung der Erfahrungen die onkologisch Behandelnde bei der Kommunikation über das Thema „Krebserkrankung und Elternschaft“ in der Routineversorgung gemacht haben, sowie deren Bewertung der Bedeutung dieses Themas; **(3)** die Entwicklung einer bedarfsgerechten Fortbildung zum Thema „Krebserkrankung und Elternschaft“, die hinsichtlich ihrer Machbarkeit und Wirksamkeit im Rahmen einer randomisiert-kontrollierten Pilotstudie evaluiert wird; und **(4)** die Entwicklung und psychometrische Überprüfung eines Instruments zur Messung der Selbstwirksamkeit von Behandelnden in ihren kommunikativen Kompetenzen.

Um das Teilziel der **Studie 1** zu erreichen, wurde eine systematische Literaturübersichtsarbeit (Publikation 2) durchgeführt, um a) zu untersuchen, welche wissenschaftlich evaluierten Interventionen (z.B. Fort- und Weiterbildungen zur Kommunikation) für Behandelnde vorliegen, die spezifische Module zu kinder- und familienbezogenen Aspekten integrieren, wenn ein Elternteil an Krebs erkrankt ist, und b) wie wirksam diese Interventionen sind. Von den neun Studien, die in diese Übersicht aufgenommen wurden, waren nur zwei Interventionen speziell entwickelt, um die Kommunikation von Behandelnden mit krebskranken Eltern minderjähriger Kinder zu verbessern. Die verbliebenen sieben enthielten lediglich ein kurzes Familienmodul, wobei die genauen Inhalte unklar blieben. Acht Studien zeigten mindestens eine statistisch signifikante Verbesserung der Kommunikation nach der Intervention, wobei die Qualität aller Studien durchschnittlich war.

In **Studie 2** wurden semistruktuierte Interviews mit N=20 Behandelnden (u.a. Ärzt:innen, Pfleger:innen, Psycholog:innen) in der Onkologie geführt, um das zweite Teilziel zu erreichen (Publikation 4). Dabei berichteten sie von ihren Erfahrungen und Einschätzungen zur Kommunikation über das Thema „Krebserkrankung und Elternschaft" in der Routineversorgung. Die Kommunikationserfahrungen der Behandelnden zeigten große Unterschiede, u.a. beeinflusst durch die Diagnose, strukturelle Herausforderungen, individuelle Merkmale der/des Patient:in und Behandelnden sowie die Berufsgruppe. Die Einschätzungen zur Relevanz dieses Themas reichten von niedriger Priorität bis hin zu hoher Bedeutung, insbesondere in palliativen Fällen. Für **Studie 3** wurde zuerst ein Studienprotokoll erstellt (Publikation 1), und auf Basis der Literaturübersicht und Interviews eine dreistündige Fortbildung in Präsenz- und E-Learning-Formaten entwickelt und diese in einer randomisiert-kontrollierten Pilotstudie mit Wartekontrollgruppe und 152 onkologisch Tätigen auf Machbarkeit und Wirksamkeit evaluiert (Publikation 3). Mittels linear gemischter Modelle zeigten beide Interventionsgruppen einen signifikanten Wissenszuwachs und eine stärkere Steigerung des Vertrauens in spezifische Kommunikationsfähigkeiten, während keine signifikanten Unterschiede in der Zufriedenheit zwischen Präsenz- und E-Learning-Fortbildung festgestellt wurden. Da ein geeigneter Fragebogen zur Messung der kommunikativen Kompetenzen von Behandelnden fehlte, wurde für **Studie 4** eine deutsche Version des Self-Efficacy Fragebogens (SE-12), den SE-12-G, entwickelt und psychometrisch evaluiert (Publikation 5). Hierfür wurde der SE-12 ins Deutsche übersetzt, an den Kontext adaptiert, um eine weitere Skala ergänzt und in kognitiven Interviews überprüft. Das Ergebnis ist ein inhaltsvalider, verständlicher Fragebogen, der die subjektiv wahrgenommenen kommunikativen Kompetenzen von Behandelnden mit zwei Subskalen misst und gute psychometrische Eigenschaften aufweist.

Die vorliegende Dissertation zeigt, dass eine Basisqualifizierung von Behandelnden in der Onkologie bezüglich kind- und elternbezogener Themen notwendig ist, jedoch bisher ein solches Trainingsprogramm fehlte. Diese Lücke schließt die bedarfsgerecht entwickelte Intervention, die das Wissen und die Kommunikationsfähigkeiten von Behandelnden in der Onkologie im Umgang mit krebskranken Eltern minderjähriger Kinder fördert. Die umfassende Evaluation zeigt, dass diese Intervention machbar und wirksam ist bezüglich der Förderung des Wissens und der Kommunikationsfähigkeiten. Weiteren Studien sind jedoch notwendig, um diese Ergebnisse zu bestätigen.

11. Publications

11.1. Publication 1 – Study protocol of Study 3 [Impact-Factor: 2.4 | UKE-Score: 15.1]

Inhestern L, **Frerichs W**, Johannsen LM, Bergelt C. (2019). *Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot-study.* BMJ Open, 9(10):e032778. doi: 10.1136/bmjopen-2019-032778.

BMJ Open

Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot study

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ABSTRACT

Introduction Patients with cancer having minor children experience particular burden and strains. Being patient and parent at the same time is associated with specific needs of support. Therefore, the communication of child-related and family-related issues plays an important role in patient care. This study aims at testing the feasibility of a training to improve the situation of patients with cancer having minor children and their families by enhancing the competencies of healthcare professionals (HCPs, eg, physicians, nurses, psychologists) in caring for patients with cancer having minor children. Moreover, the study aims at testing the study design and outcomes of the evaluation concept and preliminary effects of the training.

Methods and analysis We will conduct a randomised controlled pilot trial with three arms (face-to-face training versus web-based training versus waitlist control group) to investigate the study aims. Primary outcome will be the competency to approach child-related and family-related topics in patients with cancer measured using comprehensive case vignettes. Secondary outcomes will be communication and attitudes regarding child-related and family-related topics and self-efficacy in clinical communication skills. Outcomes will be assessed prior to the training and after the training as well as 3 months after the training. Data will be analysed using descriptive analyses, group comparisons and linear mixed models.

Ethics and dissemination The study was approved by the Local Psychological Ethics Committee of the Center for Psychosocial Medicine of the University Medical Center Hamburg-Eppendorf (LPEK-001). At the end of the study, a web-based training and a face-to-face training intervention to enhance the competencies of HCPs in caring for patients with cancer having minor children will have been systematically developed and the study design and evaluation concept will have been evaluated. The results of the study will be disseminated through peer-reviewed journals and conference presentations.

Trial registration number DRKS00015794.

Strengths and limitations of this study

- This will be the first randomised controlled pilot study to evaluate the effects of an interprofessional training to enhance health professionals' competencies in caring for patients with minor children.
- The rigorous development of case vignettes as primary outcomes and the range of secondary outcomes will provide a base for larger evaluation studies of the training programme on clinically relevant outcomes.
- Since this is a pilot study, we can only provide preliminary evidence on effects of the training. Using case vignettes instead of simulation patients for practical reasons, we will not be able to conclude on the changes in the actual behaviour of healthcare professionals when interacting with patients and families.

INTRODUCTION

Patients with cancer parenting minor children experience particular challenges and burden during the disease trajectory. Cancer and its consequences can have a great impact on the patients themselves as well as their closest relatives.[1] According to current estimates, between 14% and 18% of patients with cancer live with minor children.[2] Parents with cancer are concerned about the impact of the disease and its treatment on their children.[3 4] They experience exhaustion and feelings of guilt, as they struggle to fulfil their parental role while being patients.[5] In a phase when children need the emotional support of their parents, high risk treatments, toxicity, fatigue or other long-term physical and mental consequences of cancer may impede

parents' emotional and physical availability for their children.[6] Hence, children may have to deal with changes in daily routines (eg, loss of activities or varying carers) and emotional consequences such as fears or guilt.[7] Also, the non-ill parent is challenged by the situation and encounters multiple demands such as caring for the patient and organisation of daily life, for example, caring for the children, household requirements and job demands.[8]

According to international guidelines, psycho-oncological support is understood as an integral part of comprehensive cancer care.[9 10] Patients with cancer and their relatives should receive psycho-oncological/psycho-social support where needed. While adult relatives, mostly partners of patients with cancer, are regularly included in supportive care, support offers for minor children have scarcely been implemented into routine care.[11] In a population-based study with cancer survivors up to 6 years postdiagnosis with minor and young adult children, 73% of the survivors retrospectively reported an information need on parenting issues related to the disease or a need for family-focused/parent-focused psychosocial support during the course of the disease.[12] However, only 9% reported to have used a specific support offer.[12] A study on outpatient psychosocial counselling services in Germany reports that only about 50% of the services systematically assessed parental status in their patients.[13] Main reasons were presumed deficits in competencies and capacities of the staff.[13] A current study on healthcare professionals' (HCPs) perspective on barriers to communicate about their patients' children illustrates that structural barriers (eg, time pressure, no systematic registration or lack of training) and emotional barriers (eg, distress, professional distance) impact the communication of child-related and family-related topics.[14]

However, guidelines recommend that patient-centred communication with patients with cancer and their relatives with regard to individual needs and preferences during cancer treatment should be carried out by all professions in oncology.[9 15] Only few patients proactively address psychosocial issues to HCPs.[16] Also, patients with cancer having minor children scarcely bring up child-related or family-related concerns unsolicited.[13] At the same time, physicians and other medical staff rarely broach the issue of emotional or psychosocial topics proactively, but wait for the patients to take the initiative and disclose their psychosocial burden.[17–19] Missing routines in talking about psychosocial issues and in revealing psychosocial difficulties as well as a lack of competencies in talking about such aspects seem to be central reasons for HCPs to neglect psychosocial topics.[20] Current findings illustrate that more than 50% of the HCPs do not regularly discuss child-related aspects (eg, explanation of the disease to the child/communicating with children about the disease/disclosing cancer-related information to children) with their patients.[21] However, a recent systematic review identified the medical staff, in particular the attending physician, as a major way to access preventive family-centred or child-centred interventions.[11]

The main aim of this study is to test the feasibility of a newly developed training programme for HCPs from different professions (eg, physicians, nurses, psychologists) working with patients with cancer having minor children. The training aims at increasing the competencies to approach child-related and family-related topics during the course of the disease. For the preliminary evaluation of the effectiveness of the training, we apply Kirkpatrick's framework for training evaluation. The model is widely used[22] and comprises following levels: (1) reaction (satisfaction with the training), (2) learning (change of attitudes, improvement of knowledge and increase in skills), (3) behaviour (changes in behaviour) and (4) results (eg, improvement in patient-oriented healthcare).[23] Since the fourth level can rather be understood as improvements on organisational/system level, we refrain from evaluating the training on this level.

As the study can be considered a Phase I and Phase II study concerning the framework for design and evaluation of complex interventions,[24] a further aim is to test the feasibility of the evaluation concept including, for example, the applied outcome parameters and the measurement time points. Moreover, we explore the tendency with regard to the effectiveness of the training programme regarding the competencies to approach child-related and family-related topics, HCPs communication and attitude and self-efficacy regarding child-related and family-related topics. The intervention will be delivered either as face-to-face training or as a web-based training.

METHODS AND ANALYSIS

This study protocol is written according the SPIRIT guidelines and addresses applicable recommended items for clinical trial protocols.[25]

Study setting

The study will be conducted at the Department of Medical Psychology of the University Medical Centre Hamburg-Eppendorf in Germany.

Study design

The study is designed as a three arm randomised controlled trial (RCT). HCPs will be randomised to a face-to-face training (intervention 1), a web-based training (intervention 2) or a waitlist control group (control). Assessments will be performed at baseline (T0, before randomisation), after the training (T1) and 3 months after the training (T2) (only intervention groups). Follow-up assessment in the waitlist control group will be performed 6 weeks after baseline assessment (T1). After the intervention period, participants of the control group will be offered to participate in the web-based training or the face-to-face training. An overview of the study design and the measurement time points is displayed in figure 1.

Eligibility criteria

Eligible for the RCT are all HCPs, independent of setting (inpatient or outpatient), profession (eg, physicians,

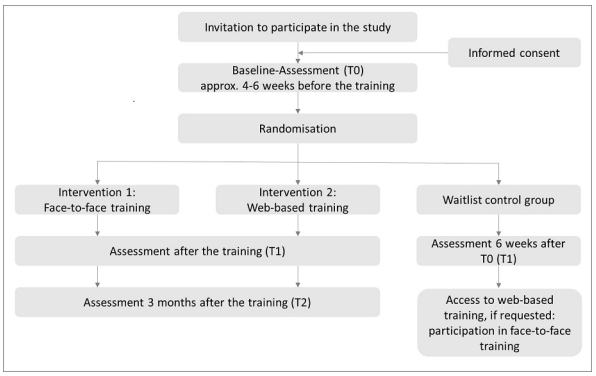

Figure 1 Flowchart of participant flow through RCT.

nurses, psychologists) or amount of work experience in the field, who provide written informed consent for study participation and work with patients with cancer. Additionally, HCPs need any available internet connection in case of being randomised to the web-based training intervention group. No further inclusion or exclusion criteria are defined.

Interventions

The interventions were developed based on a review of the recent literature as well as semistructured interviews with patients with cancer having minor children, HCPs (eg, physicians, nurses, psychosocial staff) and experts in the field of counselling families affected by parental cancer.

Face-to-face training

The face-to-face training (intervention 1) was developed based on the theoretical and empirical findings of the literature on parental cancer and the results of semistructured interviews with patients with cancer having minor children, HCPs (eg, physicians, nurses, psychosocial staff) and experts in the field of counselling families affected by parental cancer. The training consists of three modules: (1) incidences, burden and supportive care needs of patients with cancer having minor children, (2) children of patients with cancer: age-specific illness and death concepts, age-specific reactions to parental cancer, influencing factors for age-appropriate development, (3) communication in the family and communication as a HCP with the family (figure 2).

The face-to-face training will be provided in small groups (5–8 participants) by two trainers (at least one of them with expertise in the field of parental cancer and comprehensive experience in communication skills trainings) with a duration of about 3 hours. The training will be conducted as an interprofessional training to allow synergy effects by the means of different experiences and perspectives. The training adopts several didactic techniques from continuing education: lecture, video sequences of experts, group discussion and role play.[26] Participants will be encouraged to provide own examples or cases from their work experience. All participants will receive written information material

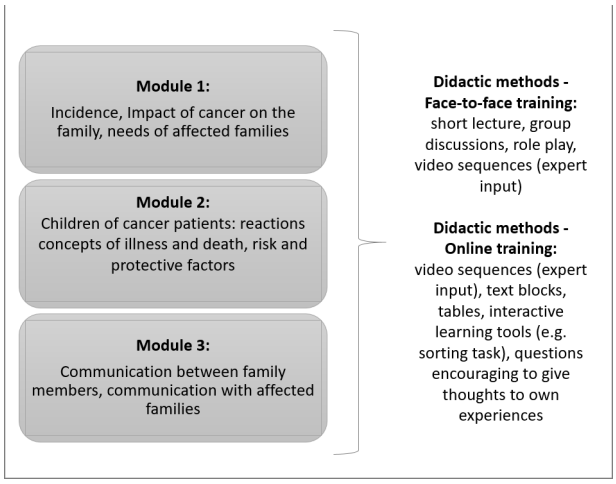

Figure 2 Content and didactic methods of the training to enhance health professionals' competencies in caring for patients with minor children.

for the training. The trainers will follow a manual which describes and defines the content and didactic elements of each module and is supported by standardised presentation material.

Web-based training

The content of the web-based training (intervention 2) was developed concordantly to the face-to-face training. The training is a self-directed web-based training that provides psychoeducational modules, exercises and questions to examine the individual level of knowledge. The web-based training includes video sequences of experts in the field of parental cancer providing commentaries or case examples. The completion of the entire web-based training will take approximately 3 hours and can be conducted in any chosen location with a PC and internet connection.

Correspondent to the face-to-face training, detailed content of the modules are conceptualised based on the results of the semistructured interviews and findings from the literature review about communication training for HCPs regarding parental cancer (figure 2).

Outcomes

Regarding the feasibility of the intervention, number of participants and dropout rates will be monitored. Training fidelity of the web-based training will be assessed by completion rates for each module and descriptive information regarding the profile of usage. Additionally, outcome parameters will be evaluated with regard to feasibility (eg, missing values, psychometric properties). Demographic data as well as professional background will be obtained.

Applying the levels of Kirkpatricks model of evaluation (table 1), the participants will complete the measures at baseline (T0), after the intervention (T1) and 3 months after T1 (T2) (figure 1, table 2).

Table 1 Level of Kirkpatrick's model and study outcome parameter

Level of Kirkpatrick's model	Outcome parameter
Level 1: Reaction Description: satisfaction with the training	Feedback concerning the training
Level 2: Learning Description: change of attitudes, improvement of knowledge and increase in skills	Competency to approach child-related and family-related topics, knowledge and relevance
	Communicative competency and self-efficacy
Level 3: Behaviour Description: changes in behaviour	Competency to approach child-related and family-related topics
	Communication and attitudes regarding child-related and family-related topics in daily practice

Primary outcome

The primary outcome competency to approach child-related and family-related topics in patients with cancer will be measured using comprehensive case vignettes developed with elements of situational judgement test (SJT) and knowledge assessment. Case vignettes have been used in several settings to evaluate training programmes and to assess the transfer of knowledge and competency in the clinical practice.[27 28]

Hence, we developed clinical case vignettes to assess in which way HCPs address child-related and family-related topics in their routine care, how they apply their knowledge about for example, age-appropriate communication to the case vignettes and how relevant they perceive child-related and family-related topics. Additionally, each case vignette comprises an element of construct driven SJTs to assess empathic reaction towards affected parents.

We developed two case vignettes for each measurement point. All six case vignettes cover typical case constellations and situations of patients with cancer having minor children. They contain a concise presentation of the case and the inclusion of hints indicating a family-related or child-related difficulty for the patient or family. The indicators of the child-related or family-related difficulty vary with regard to explicitness and clarity. The case vignettes were developed to apply to different professions working with patients with cancer (eg, physicians, nurses, psychosocial staff). Based on SJTs from assessment centres, for example, for medical students, in each vignette participants need to answer open-ended questions, multiple choice questions (eg, most appropriate reaction and importance of reaction) and forced choice questions.[29–31] Each vignette captures four domains: (1) transfer of knowledge into clinical practice, (2) empathic behaviour towards affected parents, (3) integration of child-related and family-related topics into clinical practice, (4) perceived relevance of integrating child-related and family-related topics into clinical practice.

Each participant will receive a sum score in each domain based on the two vignettes of each measurement point.

Table 2 Study measurements and measurement points

Assessment	Baseline (T0)	After the training (IG)/6-week follow-up (CG) (T1)	3-month follow-up (T2)
Sociodemographic and occupational variables	●		
Changes in sociodemographic or occupational situation		●	●
Primary outcome			
Competency regarding child-related and family-related topics (case vignettes/SJT)	●	●	●
Secondary outcomes			
Communicative competency and self-efficacy	●	●	●
Knowledge regarding child-related and family-related topics	●	●	●
Communication and attitudes regarding child-related and family-related topics in daily work	●	●	●
Covariates			
Professional fulfilment Index	●	●	●
Interprofessional teamwork	●	●	●
Feedback concerning the training*		●	

*Only in the intervention groups.
CG, waitlist control group; IG, intervention groups; SJT, situational judgement test.

Comparisons of the scores between the three measurement points illustrate positive or negative changes. The developed case vignettes were discussed within the research team (including several team members with clinical experience in the field) with regard to comprehensibility, relevance, fairness, level of difficulty and authenticity. In a second step, the case vignettes were pilot tested by 2–3 HCPs and afterwards finalised.

Secondary outcomes

Communicative competency and self-efficacy

Communicative competency will be measured with the translated version of a questionnaire on self-efficacy in HCPs' clinical communication skills (SE-12).[32] Additionally, specific communication competencies concerning child-related and family-related topics will be assessed with questions inspired by items of the self-efficacy questionnaire regarding communication skills about existential issues in cancer care by Hvidt and colleagues[33] and a self-efficacy questionnaire for clinical communication skills with parents of childhood patients with cancer.[34] All items were translated into German following the TRAPD translation protocol.[35 36]

Knowledge about child-related and family-related topics

To assess the knowledge about child-related and family-related topics, we developed items based on the information provided in the training. Questions are based on findings from scientific publications on the topic of parental cancer and cover, for example, incidence of parental cancer, the impact of cancer on affected parents and their children and risk factors for maladjustment in children.

Communication and attitudes regarding child-related and family-related topics in daily practice

HCPs' attitudes and behaviours during daily work routines will be assessed using self-developed items. The items include questions such as 'How often do you ask your patients about the needs of their children or family?' and can be answered on a 4-point-likert scale (never, sometimes, often and always).

Covariates

Professional fulfilment

HCPs' professional fulfilment will be assessed using the translated version of the Professional Fulfillment Index, a 16-item instrument with three subscales for professional fulfilment, work exhaustion and interpersonal disengagement.[37] The questionnaire was translated using the TRAPD translation protocol.[35 36]

Interprofessional teamwork

To assess attitudes towards interprofessional teamwork, we developed task specific items based on HCPs' attitude about HCPs' responsibilities concerning child-related and family-related topics, for example, identifying supportive care needs of patients' families.

Participants' feedback

To assess the feedback and evaluation concerning content and organisation of the training, we use self-developed items with regard to the content related to clinical practice, overall impression of the content, organisation and structure of the training, the evaluation of single components of the training and atmosphere during the training. Items are adjusted for kind of intervention (face-to-face training or web-based training). Additionally, participants have the opportunity to comment on the training (open question: general/additional comments).

Sample size

As we cannot assume any effects a priori, we use the approach for pilot studies by Viechtbauer and colleagues[38] to determine the sample size. The calculation implicates the identification of unforeseen problems such as incomplete data sets or ambiguous inclusion criteria or misinterpretation of questionnaire items. Assuming a 10% probability for an unforeseen problem to occur and a 95% CI to detect these problems, a sample size of n=30 participants in each group is required. Considering a dropout rate of 30%, n=108 participants (n=36 per group) need to be included in the study.

Recruitment

HCPs working with patients with cancer will be identified through existing and re-established collaborations with clinics and other (psycho-) oncological institutions (eg, practices of haematology and oncology or psycho-oncological outpatient counselling services) in Hamburg and the surrounding area. Eligible HCPs will be contacted and informed about the study by email, letter or telephone. If interested in participation, a member of the research team will contact the HCPs and will send a detailed information letter and informed consent form. HCPs participating in the study will be informed that there is an equal chance to be assigned to one of the three groups (intervention 1, intervention 2, control). HCPs of the waitlist control group can participate in one of the interventions after completion of the T1 questionnaire.

The research team can be contacted in case of questions regarding the study. HCPs who do not react after receiving the information letter/email will be followed-up by an additional contact (telephone, email or letter) and asked about their interest to participate. In case of consent to participate, HCPs will be enrolled into the study and receive the baseline assessment.

Randomisation and blinding

Participants will be randomised in a 1:1:1 ratio into the three study groups. As we follow a continuous enrolment strategy, each newly enrolled HCP will be randomly assigned based on a computer-based randomisation protocol using the statistical programme R. Randomisation will be stratified with regard to profession to ensure a well-adjusted representation of the different professions between groups. A collaborator from the statistical

methods-research group of the Department of Medical Psychology of the University Medical Center Hamburg-Eppendorf, who is otherwise not involved in the study in any way, will perform the randomisation and intervention allocation to ensure independency from recruitment of the HCPs and realisation of the intervention. Following the randomisation, blinding of the participants and the research team cannot be implemented due to the nature of the intervention.

Data management and monitoring

The members of the research team will continuously document the data collection and manage the data collection at the different measurement points. Questionnaires will be entered in a SPSS database by research assistants. To assure high data quality, double entry will take place for some questionnaires (20%) and checked for mistakes. Data are only accessible to members of the research team. Using a data-cleaning protocol based on syntax, the plausibility of the data will be checked for example, with regard to value range or inconsistencies.

As the training will involve HCPs and comprises an intervention with no known/minimal risks, a data monitoring committee was not included. Adverse events will be monitored, documented and the necessity of adaptation in the study process will be discussed within the research team.

Analyses

Descriptive statistics will be used to analyse the parameters regarding the feasibility and the appraisal of the intervention (eg, organisation, content). Moreover, psychometric properties of the questionnaires in the study sample will be analysed. Descriptive statistics will be reported to characterise the sample. Mean and SD will be reported for continuous data and frequencies and percentages for categorical data. Group comparisons will be conducted using χ^2, U or t-tests, depending on the scale level. We will use linear mixed models to analyse the outcomes with time and study group (intervention group 1, intervention group 2, control group; baseline, postintervention, 3-month postintervention) as fixed factors. Preliminary effects will be calculated for all outcome measures. All analyses will be performed using the intent-to-treat approach. Additionally, exploratory predictor analyses using regression analyses will be conducted.

Patient and public involvement statement

We did not involve patients or the public in our work.

ETHICS AND DISSEMINATION

Ethics approval and consent to participate

The study was approved by the Local Psychological Ethics Committee of the Center for Psychosocial Medicine of the University Medical Center Hamburg-Eppendorf (LPEK-001). Informed consent will be obtained from each HCP prior to participation in the study.

Confidentiality

Data protection is assured by pseudonymisation and restricted access authorisation. The code list can only be decrypted by an authorised associated member of the study team without any research interest in the presented study. The code list will be destroyed after the end of the data collection.

Availability of data and material

The research team will have full access to the dataset. However, availability of these data will be restricted and data will not be publicly available. Data are, however, available from the authors on reasonable request and with permission of Local Psychological Ethics Committee (LPEK) and the data protection officer of the University Medical Center Hamburg-Eppendorf.

Dissemination

The findings of our study will be presented on national and international conferences and published in scientific journals. Publications will address the main aims of the study. Moreover, analyses of detailed aspects with data derived from the study will be published.

The results of our study will allow conclusions on the feasibility of similar trials and study designs. Moreover, we will systematically investigate the preliminary effects of an interprofessional training with focus on patients with cancer having minor children.

DISCUSSION

Psycho-oncological support for patients and their relatives is an integral part of comprehensive cancer care.[9 15 39] Patients with cancer parenting minor children have specific concerns and encounter specific challenges as they experience a double burden of being a patient and being a parent.[3 5] Still, support services for affected parents and their children are not routinely implemented in cancer care.[11 13] HCPs should support patients and their families to receive healthcare according to their psychosocial needs. This means that HCPs should identify psychosocial needs by assessing and communicating these topics openly and proactively. If specific psychosocial support is indicated to maintain mental health or reduce disruptions in daily life (eg, child care), referral to psycho-oncological treatment, child-centred counselling or social legal advice is necessary. The content of the developed training was conceptualised based on the results of semistructured interviews with patients, HCPs with different professions and experts in the field of parental cancer. This approach allowed to design the content of the training based on the working experience of the target group.

With this pilot study, we will evaluate a newly developed training for HCPs to enhance their competencies regarding child-related and family-related topics and examine preliminary effects of a face-to-face training and a web-based training. The results of the pilot study will

provide relevant information on feasibility and preliminary evidence on the effect of the training. These information may provide a base for further interventional studies for the developed training.

The trial has several limitations. Due to the nature of the intervention, HCPs are not blinded for their intervention, which may impact the results. Moreover, the training is not mandatory and HCPs who are motivated and interested in the topic will possibly participate more frequently. Randomisation will be conducted on an individual level, which may lead to contamination if colleagues who participate are randomised to a comparison group. To evaluate the competencies, we use case vignettes instead of simulation patients for practical reasons. Hence, we will not be able to conclude on the changes in the actual behaviour of HCPs interacting with patients and families.

However, to the best of our knowledge, this is the first randomised controlled pilot trial for a training for HCPs in oncology to enhance their competencies in caring for patients with minor children. So far, only few studies have focused on this topic and have not included any control group.[17 40]

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REFERENCES

1 Rolland JS. Cancer and the family: an integrative model. *Cancer* 2005;104:2584–95.
2 Weaver KE, Rowland JH, Alfano CM, *et al*. Parental cancer and the family: a population-based estimate of the number of US cancer survivors residing with their minor children. *Cancer* 2010;116:4395–401.
3 Muriel AC, Moore CW, Baer L, *et al*. Measuring psychosocial distress and parenting concerns among adults with cancer: the parenting concerns questionnaire. *Cancer* 2012;118:5671–8.
4 Inhestern L, Bultmann JC, Beierlein V, *et al*. Psychometric properties of the parenting concerns questionnaire in cancer survivors with minor and young adult children. *Psychooncology* 2016;25:1092–8.
5 Semple CJ, McCance T. Parents' experience of cancer who have young children: a literature review. *Cancer Nurs* 2010;33:110–8.
6 Moore CW, Rauch PK. Addressing parenting concerns of bone marrow transplant patients: opening (and closing) Pandora's box. *Bone Marrow Transplant* 2006;38:775–82.
7 Visser A, Huizinga GA, van der Graaf WTA, *et al*. The impact of parental cancer on children and the family: a review of the literature. *Cancer Treat Rev* 2004;30:683–94.
8 Aamotsmo T, Bugge KE. Balance artistry: the healthy parent's role in the family when the other parent is in the palliative phase of cancer — challenges and coping in parenting young children. *Pall Supp Care* 2014;12:317–29.
9 National Compehensive Cancer Network. NCCN guidelines for patients: distress. National Compehensive cancer network, 2017. Available: www.nccn.org/patients/guidelines/distress/index.html [Accessed Jun 2019].
10 National Breast Cancer Centre and National Cancer Control Initiative. Clinical practice guidelines for the psychosocial care of adults with cancer. Camperdown: National breast cancer centre, 2003. Available: canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/clinical-practice-guidelines-psychosocial-care-adults-cancer [Accessed Jun 2019].
11 Inhestern L, Haller A-C, Wlodarczyk O, *et al*. Psychosocial interventions for families with parental cancer and barriers and facilitators to implementation and use – a systematic review. *PLoS One* 2016;11:e0156967.
12 Ernst JC, Beierlein V, Romer G, *et al*. Use and need for psychosocial support in cancer patients: a population-based sample of patients with minor children. *Cancer* 2013;119:2333–41.
13 Ernst JC, Beierlein V, Romer G, *et al*. Krebskranke Eltern und ihre minderjährigen Kinder - eine bundesweite Befragung ambulanter psychosozialer Krebsberatungsstellen zu Bedarf und Inanspruchnahme. *Gesundheitswesen* 2012;74:742–6.
14 Dencker A, Rix BA, Bøge P, *et al*. A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children. *Psychooncology* 2017;26:2162–7.
15 Deutsche Krebsgesellschaft e.V. (DKG), Deutsche Krebshilfe e. V. (DKH), Leitlinienprogramm Onkologie der Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF). S3 Leitlinie für Psychoonkologische Diagnostik, Beratung und Behandlung von erwachsenen Krebspatienten, Langversion 1.1. Leitlinienprogramm Onkologie, 2014. Available: https://www.awmf.org/uploads/tx_szleitlinien/032-051OLl_S3_Psychoonkologische_Beratung_Behandlung_2014-01_abgelaufen.pdf [Accessed Jun 2019].
16 Maguire P. Improving communication with cancer patients. *Eur J Cancer* 1999;35:1415–22.
17 Turner J, Clavarino A, Butow P, *et al*. Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention. *Eur J Cancer* 2009;45:1798–806.
18 Detmar SB, Aaronson NK, Wever LDV, *et al*. How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality-of-life issues. *JCO* 2000;18:3295–301.
19 Butow PN, Brown RF, Cogar S, *et al*. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology* 2002;11:47–58.
20 Fagerlind H, Kettis Åsa, Glimelius B, *et al*. Barriers against psychosocial communication: oncologists' perceptions. *JCO* 2013;31:3815–22.
21 Schouten B, Bergs J, Vankrunkelsven P, *et al*. Healthcare professionals' perspectives on the prevalence, barriers and management of psychosocial issues in cancer care: A mixed methods study. *Eur J Cancer Care* 2019;28:e12936.
22 Campbell K, Taylor V, Douglas S. Effectiveness of online cancer education for nurses and allied health professionals; a systematic review using Kirkpatrick evaluation framework. *J Cancer Edu*.
23 Kirkpatrick DL, Kirkpatrick JD. *Evaluating training programs*. 3rd edn. San Francisco: Berrett-Koehler, 2006.
24 Craig P, Dieppe P, Macintyre S, *et al*. Developing and evaluating complex interventions: the new medical Research Council guidance. *BMJ* 2008;337.
25 Chan A-W, Tetzlaff JM, Altman DG, *et al*. Spirit 2013 statement: defining standard protocol items for clinical trials. *Ann Intern Med* 2013;158:200–7.
26 Marinopoulos SS, Dorman T, Ratanawongsa N, *et al*. Effectiveness of continuing medical education. *Evid Rep Technol Assess* 2007;149:1–69.
27 Sowden GL, Vestal HS, Stoklosa JB, *et al*. Clinical case Vignettes: a promising tool to assess competence in the management of agitation. *Acad Psychiatry* 2017;41:364–8.
28 Peabody JW, Luck J, Glassman P, *et al*. Comparison of vignettes, standardized patients, and chart abstraction: a prospective validation study of 3 methods for measuring quality. *JAMA* 2000;283:1715–22.
29 Bledow R, Frese M. A situational judgment test of personal initiative and its relationship to performance. *Pers Psychol* 2009;62:229–58.

30 Hauenstein NMA, Findlay RA, McDonald DP. Using situational judgment tests to assess training effectiveness: lessons learned evaluating military equal opportunity advisor trainees. *Military Psychology* 2010;22:262–81.
31 Lievens F, Coetsier P. Situational tests in student selection: an examination of predictive validity, adverse impact, and construct validity. *Int J Sel Assess* 2002;10:245–57.
32 Axboe MK, Christensen KS, Kofoed P-E, *et al*. Development and validation of a self-efficacy questionnaire (SE-12) measuring the clinical communication skills of health care professionals. *BMC Med Educ* 2016;16:272.
33 Hvidt EA, Ammentorp J, Søndergaard J, *et al*. Developing and evaluating a course programme to enhance existential communication with cancer patients in general practice. *Scand J Prim Health Care* 2018;36:142–51.
34 Ammentorp J, Sabroe S, Kofoed P-E, *et al*. The effect of training in communication skills on medical doctors' and nurses' self-efficacy. *Patient Educ Couns* 2007;66:270–7.
35 Harkness J, Pennell BE, Schoua-Glusberg A. Survey questionnaire translation and assessment. In: Presser S, Couper M, Lessler J, eds. *Methods for testing and evaluating survey questionnaires*. Hoboken, New Jersey: John Wiley & Sons, 2004: 453–73.
36 Mohler P, Dorer B, De Jong J, *et al*. Translation. guidelines for best practice in cross-cultural surveys. Ann Arbor, MI: survey research center. Institute for social research. University of Michigan, 2016. Available: http://www.ccsg.isr.umich.edu/ [Accessed Jun 2019].
37 Trockel M, Bohman B, Lesure E, *et al*. A brief instrument to assess both burnout and professional fulfillment in physicians: reliability and validity, including correlation with self-reported medical errors, in a sample of resident and practicing physicians. *Acad Psychiatry* 2018;42:11–24.
38 Viechtbauer W, Smits L, Kotz D, *et al*. A simple formula for the calculation of sample size in pilot studies. *J Clin Epidemiol* 2015;68:1375–9.
39 National Institute for Clinical Excellence. Improving supportive and palliative care for adults with cancer. National Institute for Cinical excellence, 2004. Available: https://www.nice.org.uk/guidance/csg4 [Accessed Jun 2019].
40 Grant L, Sangha A, Lister S, *et al*. Cancer and the family: assessment, communication and brief interventions—the development of an educational programme for healthcare professionals when a parent has cancer. *BMJ Support Palliat Care* 2016;6:493–9.

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PLOS ONE

RESEARCH ARTICLE

Child- and family-specific communication skills trainings for healthcare professionals caring for families with parental cancer: A systematic review

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Abstract

Introduction

As part of high-quality cancer care, healthcare professionals (HCPs) play a significant role in identifying and addressing specific needs of cancer patients parenting minor children. However, HCPs experience various barriers to adequately support parents with cancer. This systematic review explores current CSTs incorporating child- and family- specific modules for HCPs in oncology. Moreover, outcome measures and effectiveness of trainings are systematically investigated.

Methods

The systematic review was registered within PROSPERO (registration code: CRD42020139783). Systematic searches were performed in four databases (PubMed, Cinahl, PsycInfo, Web of Science) in 12/2020, including an update in 12/2021 and 08/2022. Quantitative, primary studies fulfilling the pre-defined inclusion criteria were included. Due to the expected heterogeneity a meta-analysis was not conducted. Study selection and quality assessment were conducted by two independent researchers, data extraction by one. Study quality was assessed using an adapted version of the National Institutes of Health quality assessment tool for pre-post studies without control group.

Results

Nine studies were included in this review following an experimental pre-post design only. Two CSTs were specifically designed to improve communication with cancer patients parenting minor children, the remaining seven incorporated a brief family module only. Seven programs were face-to-face trainings, one an e-learning and one a webinar. Eight studies found at least one statistically significant improvement in communication after training. However, quality of most studies was fair.

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Abbreviations: COMFORT, COMFORT TM SM Communication Curriculum; COMSKIL, COMSKIL training program; CST, Communication skills training; GHQ, General Health Questionnaire 28; HCPs, Healthcare professionals; MBI, Maslach Burnout Inventory; NIH, National Institutes of Health.

Conclusion

This is the first review exploring specific CSTs for HCPs caring for cancer patients parenting minor children. As only two CSTs focused on parental cancer, evidence on the effectiveness of such CSTs is limited. Existing CSTs should be evaluated properly and include details on content of family modules. Further studies including and evaluating specific CSTs focusing on parental cancer are needed in order to strengthen HCPs' competencies to meet specific needs of patients parenting minor children.

Introduction

Approximately 14–25% parents with dependent children are diagnosed with cancer [1–3] which can have a major impact on the entire family. Cancer patients parenting minor children experience increased levels of stress and anxiety compared to patients without minor children [4, 5]. Additional to the burden of the life-limiting disease and its treatment, parents with cancer worry about how to maintain family life and their role as a "good" parent and supporter [6–9]. Parents often feel insecure if, when and how to communicate with their children about cancer and how to adequately address their children's needs [8, 10, 11].

Children of parents having cancer experience major challenges in their family routine and increased psychosocial stress [6, 12]. Even without knowing, they feel that something serious is going on [13]. Providing age-appropriate information and timely communication about parental cancer can decrease the risk of developing negative psychological and physical consequences in affected children [12, 14].

Healthcare professionals (HCPs) have a significant role in identifying patients parenting minor children, their specific needs and—if necessary—initiating supportive, psychosocial care [1, 6, 8, 11]. In order to provide high-quality, patient-centred cancer care, involvement of family and their specific needs is essential [15, 16]. Family members are often the primary support for cancer patients [17] and act as caregiver and thus are impacted by cancer as well [18]. As family communication is associated with relationship functioning and adjustment to the cancer diagnosis [18], it is essential for HCPs to provide support to cancer patients and their families on family communication issues, e.g., open communication. In order to identify potential cancer patients parenting minor children, it is key to know about the patient's family status and if applicable to proactively address child- and family specific themes within cancer care. Previous studies show that parents with cancer wish for support and guidance from their HCPs about child- and family-specific aspects, especially on communication with their children [1, 9, 10, 19]. However, current results show that less than 50% of HCPs routinely communicate about child- and family-specific themes with their patients [20]. Barriers of HCPs to include child- and family-specific aspects routinely in cancer care are e.g., lack of specific competencies and knowledge as well as time pressure or structural barriers [8, 11, 21, 22]. Additionally, other studies report that HCPs feel insufficiently trained in providing basic adequate psychosocial support to cancer patients parenting minor children [11, 23].

In order to address these major barriers in HCP's communication about child- and family-specific aspects, adequate trainings are needed to improve communication skills and competencies for HCPs in oncology [10, 24].

Over the last decade, various communication skills trainings (CSTs) have been developed and implemented to improve communication skills in oncology. Findings indicate

improvements in HCP's communication skills, namely increasing empathy [25], knowledge and self-efficacy [26] or in certain patient-reported outcomes, e.g., patient satisfaction [26].

Considering the described relevance and specific burden of affected parents, CSTs should also address these aspects. However, despite many CSTs being developed for HCPs in oncology in recent years [25–27], it remains unclear whether and to what extent child- and family-related aspects are addressed in these CSTs and previous reviews on CSTs have not included this topic [25].

To close this gap, this systematic review aims to a.) provide an overview of existing CSTs for HCPs working in oncology addressing child- and parent-specific aspects in cancer care, b.) explore reported outcome measures associated with the CSTs and c.) gather existing evidence of effectiveness of these trainings.

Materials and methods

The systematic review was registered in the International Prospective Register of Systematic Reviews (PROSPERO, registration code: CRD42020139783) and follows the updated guideline for reporting systematic reviews (PRISMA 2020 statement [28]).

Data sources and search strategy

An electronic literature search was performed in the databases of PubMed, Cinahl, PsycInfo and Web of Science with no limitation regarding the publication year. The search was conducted on December 9th, 2020, was developed in PubMed and adapted to the other databases. A search update was conducted on December 3rd, 2021 and on August 12th 2022. A librarian of the Central Medical Library Hamburg was consulted to review the final search strategy.

The systematic search strategy consisted of a combination of different terms and keywords from the following four domains: (i) communication skills training, (ii) healthcare professional, (iii) oncology, and (iv) parent/family (see Table 1).

Articles on pediatric oncology as well as qualitative studies were excluded. Our primary electronic search strategy was complemented by a hand search, consisting of citation tracking of included articles.

Eligibility criteria and study selection

Due to language restriction of the authors, peer-reviewed publications in English or German were retrieved. We included studies reporting any type of CST with a pre-post design (e.g., single arm intervention studies or studies including a control group) regarding outcomes assessing change of communication competencies, comprising at least one module on child- or parent-specific aspects in cancer care for HCPs caring for adult cancer patients. The applied in- and exclusion criteria are displayed in Table 2. However, despite our extensive search strategy only two studies were identified during the study selection process to focus on child- and parent-specific aspects within their CSTs. Therefore, we decided to broaden the focus of this systematic review and to include studies, which entail a child- and family-specific module within their CST.

To manage and facilitate the selection process, search results were imported into the reference management software EndNote (Version EndNote X9.3.2) and duplicates were removed. One author (WF) conducted the title and abstract screening. All potentially relevant articles according to the defined inclusion and exclusion criteria were included for full text screening. Full texts were independently assessed for eligibility by two reviewers (WF, WG). Disagreement between reviewers was resolved by discussion; where necessary, a third reviewer (LI) was consulted.

Table 1. Search strategy exemplary for the database Pubmed, adjusted according to other electronic databases.

Search Strategy	
#1	communication[Title/Abstract] OR "talking"[Title/Abstract] OR "talk*"[Title/Abstract] OR "competenc*"[Title/Abstract] OR "skill*"[Title/Abstract] OR "consultat*"[Title/Abstract] OR "communication"[MeSH Major Topic] OR "education, medical, continuing"[MeSH Major Topic] OR "education, nursing, continuing"[MeSH Major Topic]
#2	train*[Title/Abstract] OR training[Title/Abstract] OR education*[Title/Abstract] OR seminar*[Title/Abstract] OR program*[Title/Abstract] OR teach*[Title/Abstract] OR workshop*[Title/Abstract] OR cours*[Title/Abstract] OR develop*[Title/Abstract] OR intervention*[Title/Abstract] OR manual*[Title/Abstract] OR plan*[Title/Abstract] OR instruction*[Title/Abstract] OR curriculum*[Title/Abstract] OR e-learning[Title/Abstract] OR electronic learning[Title/Abstract] OR online[Title/Abstract] OR web-based[Title/Abstract] OR webbased[Title/Abstract] OR tool*[Title/Abstract]
#3	(#1 AND #2) OR "communication skill* training*"
#4	(health[Title/Abstract] OR healthcare[Title/Abstract] OR health care[Title/Abstract]) AND (personnel[Title/Abstract] OR staff[Title/Abstract] OR provider*[Title/Abstract] OR professional*[Title/Abstract]) OR oncologist*[Title/Abstract] OR oncolog*[Title/Abstract] OR nurs*[Title/Abstract] OR doctor*[Title/Abstract] OR practitioner*[Title/Abstract] OR medical[Title/Abstract] OR psychologist*[Title/Abstract] OR psychological[Title/Abstract] OR social work*[Title/Abstract] OR "health personnel"[MeSH Major Topic]
#5	"parenting"[MeSH Major Topic] OR "parent*"[Title/Abstract] OR "mom*"[Title/Abstract] OR "dad*"[Title/Abstract] OR "mother*"[Title/Abstract] OR "father*"[Title/Abstract] OR "famil*"[Title/Abstract] OR "matern*"[Title/Abstract] OR "patern*"[Title/Abstract]
#6	("medical oncology"[MeSH Major Topic]) OR ("oncology nursing"[MeSH Major Topic])) OR ("cancer survivors"[MeSH Major Topic])) OR ("cancer"[Title/Abstract])) OR (oncolog*[Title/Abstract])) OR (tumor*[Title/Abstract])) OR ("tumour"[Title/Abstract])) OR ("leukeamia"[Title/Abstract])) OR (palliativ*[Title/Abstract])) OR (metastat*[Title/Abstract])) OR (malign*[Title/Abstract])
#7	#3 AND #4 AND #5 AND #6
#8	#7 NOT (pediatric[Title/Abstract])
#9	#8 NOT (qualitative[Title])

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Table 2. Inclusion and exclusion criteria.

Inclusion	Exclusion
Study type and design	
Quantitative intervention studies	Qualitative studies, observational studies without intervention, studies without a pre-post measurement of outcomes
	Study is not cancer specific (e.g., mental illness)
	Dissertations, conference abstracts etc.
Participants	
Healthcare professionals (HCPs) working in oncology or with cancer patients (e.g., nurses, physicians)	HCPs not working with cancer patients or not having any experience caring for cancer patients
HCPs within healthcare educational programmes (e.g., nursing or medical students);	HCPs working in paediatrics
HCPs working in all settings (e.g., outpatient, inpatient)	
Interventions	
Studies evaluating a communication training or educational program including at least a module on child-, parent- or family-specific themes;	Intervention is not a communication skills training or is not an educational intervention to improve HCPs' communication with cancer patients
Intervention aims to improve healthcare professional's communication skills, behavior or knowledge	Intervention aimed to improve communication within paediatric oncology
Date	
No restrictions	
Language	
English or German	
Availability	
Fulltext needs to be available (e.g., contact by e-mail to corresponding author)	
Study must be published in a peer-reviewed journal	

https://doi.org/10.1371/journal.pone.0277225.t002

Data extraction and synthesis

As we were expecting a large heterogeneity of studies including a large variation in participants, outcome measures or type of CST being used, we synthesized findings of the included studies in the form of a narrative review. A data extraction form was developed including the following information: aims/background, study design and methods; details of CST (e.g., development, setting, duration, content, teaching strategies); details on child- and family-specific module; characteristics of participants; CST outcome measures and results. The form was independently pilot tested by two reviewers (WF, WG) with one randomly selected study included in this review. Data extraction of included studies was systematically performed by one reviewer (WF), final results were discussed with two other reviewers (WG, LI).

Intervention outcomes and findings were categorized based on Kirkpatrick's framework for training evaluation based on the following levels: 1. Reaction–Participant's satisfaction with the training; 2. Learning–Participant's change of attitudes, increase in knowledge and skills; 3. Behavior–Participant's change in behavior; 4. Results–other improvements in patient-oriented healthcare (e.g., participants well-being) [29].

Quality assessment

Methodological quality of included studies was independently assessed by two reviewers (WF, WG) using a slightly modified version of the National Institutes of Health (NIH) quality assessment tool for pre-post studies without control group [30]. This tool was selected as all included studies were quasi-experimental studies with a pre-post design. none including a control group. Study quality could be rated as good, fair or poor. Any disagreement between reviewers was resolved by discussion and, where necessary, a third reviewer (LI) was consulted.

Results

The main literature search identified two studies specifically addressed the subject of cancer patients parenting minor children within their CST and five studies incorporated a brief family module within their CST. The first update added another two studies evaluating a CST for HCPs in oncology, including a brief module on family-specific aspects in cancer care. In total, nine studies were included in this review (Fig 1).

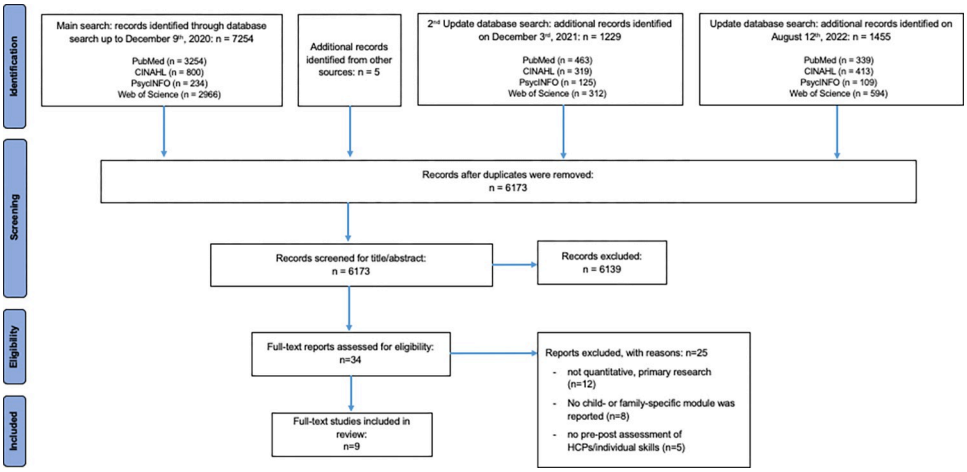

Fig 1. PRISMA flow diagram for systematic reviews.

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Description of included studies

Table 3 gives an overview of included studies. All included studies were published between 2008 and 2021. Five studies were conducted in the North America [31–35], two in Australia [23, 36], one in Africa [37] and one in Europe [38]. Included studies used a quasi-experimental design with pre-post measurement only and no studies were identified including a control-group.

Participants

Most studies included qualified HCPs [23, 31, 33–36, 38], two studies included nursing students only [32, 35] (see Table 3). In total, 1578 HCPs participated in the included studies. Six studies including nursing professionals only [23, 31–35], three studies including HCPs of various disciplines (e.g., nurses, doctors, social workers) [36–38], in which there was a high proportion of nurses (e.g. [38]). In two studies only female HCPs participated [33, 34], four other studies included mainly female participants (range 75–97% [23, 32, 35, 36]). In studies reporting on mean age of participants, mean age ranged from 24 to 47 years [23, 32, 34, 35]. Professional experience varied from overall working experience [37] to working in oncological setting [23, 33, 38] or in palliative care [34]. Two studies assessed previous communication skills training participation [34, 38]. One study assessed if participants had currently a serious illness in family member (34%) and previous history of bereavement of a first degree relative (51%) [23].

CST characteristics

Of the nine included studies, one training was an e-learning training [35] and one a webinar series [37]. The remaining CSTs were face-to-face trainings [23, 31–34, 36, 38]. The duration of the programs varied substantially in length, ranging from 30–40 minutes [38] to a 2-day program [36]. Group size of trainings varied between studies, with small groups of n = 3–8 participants each [23, 33, 34, 36, 38] and large groups of e.g., up to n = 158 participants per training [36]. The content of the CSTs was either developed based on a literature review [23, 31, 35, 36, 38], a needs assessment (e.g., focus group or survey [23, 31, 32]) or input through a workshop with experts [23, 35, 36]. One study reported on pilot-testing their intervention [35].

Detailed description of the CSTs, outcome measurements and results of the included studies are presented in Table 4.

Content and development of the CSTs including a child- or family-specific module

Of the nine studies included, only two included a CST for HCPs specifically addressing the subject of cancer patients parenting minor children [23, 38]. The remaining seven studies incorporated a brief family module within their CST. This brief family module often entailed themes e.g., how to communicate with families of cancer patients [31, 32, 35–37] or how to involve the family in cancer care [33, 34]. Detailed information if and in which way the family modules refer to children as relatives in particular or if parental issues were covered was not reported within the studies.

Two studies [31, 32] applied the COMSKIL training program [39] and four [33–35, 37] the original or an adapted version of COMFORT $^{TM\ SM}$ Communication Curriculum [40], a CST specifically designed for nurses. Three studies developed their own CST program [23, 36, 38]. The description of the family module differed slightly between studies using the original

Table 3. Characteristics of the included studies.

Author, Year Title	Country	Design	Name of CST	Child- or family-specific module	Participants (HCPs)	N of participants	Participants characteristics	CST duration, setting, group size, number of sessions	Quality assessment NIH score
Banerjee et al., 2017 The implementation and evaluation of a communication skills training program for oncology nurses	USA	Quasi-experimental Pre-Post Evaluation	adapted COMSKIL	Responding to challenging interactions with families (one of three modules)	Oncology nurses from various inpatient settings (e.g., acute care, pediatrics) at MSKCC	342	N/R	1-day Face to face ≈12 nurses per training	poor
Cannity et al., 2021 Acceptability and efficacy of a communication skills training for nursing students: Building empathy and discussing complex situations	USA	Single-arm pre-post design	adapted COMSKIL	Responding to challenging interactions with families (one of three modules)	Nursing students from a large cancer center in the northeastern United States; as part of their clinical education during their final year of bachelor nursing education	158	87% female Average age 23.7 years (SD = 3.70) 84% white/Caucasian 9% Latino 4% Asian/ Asian-.American 1% black/African-American	1-day Face-to-face Participants per training = NR	fair
Cronin & Finn, 2017 Implementing and Evaluating the COMFORT Communication in Palliative Care Curriculum for Oncology Nurses	USA	Quasi-experimental Pre-Post Evaluation	adapted COMFORT	Module F: incorporating family into plans of care, understanding characteristics of various caregivers	Nurses from 2 oncology units in palliative care	20	100% female Age: 60% of 21–29 years; 90% white/ Caucasian, 10% African American; Professional experience: as practicing nurse 0–5 years = 80%, as oncology nurse 0–5 years = 85%; Highest level of education: 5% associate degree, 70% bachelor's degree, 25% master's degree;	4 hours Face-to-face ≈5 nurses per training	fair
Fuoto & Turner, 2009 [34] Palliative Care Nursing Communication: An Evaluation of the COMFORT Model	USA	Quasi-experimental Pre-Post Design	COMFORT	Family: support caregiver involvement and understanding	Nurses from one palliative care unit in a large tertiary care center	14	100% female Age: *M* 46.9 years (SD 11.9) Employment as registered nurse in years: mean 16.5 (SD 9.9), in palliative care: mean 3.2 (SD 4.4); highest level of education: 36% associate degree, 50% bachelor's degree, 14% master's degree; 100% of HCPs reported on at least 1 previous CST	4 hours Face-to-face ≈4–6 nurses per training	fair

(*Continued*)

Table 3. (Continued)

Author, Year Title	Country	Design	Name of CST	Child- or family-specific module	Participants (HCPs)	N of participants	Participants characteristics	CST duration, setting, group size, number of sessions	Quality assessment NIH score
Quinn et al., 2008 "Palliative care: the essentials": evaluation of a multidisciplinary education program	Australia	Quasi-experimental Pre-Post Design	"Palliative Care: The Essentials"	Session IV: Family-centered care Session VI: Communicating with patients, families and colleagues Session IV: Care of an imminently dying person and their family	All HCPs with university degree (or equivalent)	495 (Nurses = 402, allied HCPs = 44, doctors = 8, other staff = 41)	96% female Age: 60% between 40–59 years	2-day program Face-to-face 4 trainings of 92–158 HCPs each	fair
Semple et al., 2017 How education on managing parental cancer can improve family communication	Northern Ireland	Quasi-experimental Pre-Post Design	Educational intervention for HCPs to communicate with parents diagnosed with cancer	Specific CST to communicate with parents diagnosed with cancer	Oncology professionals	259 in total (registered nurses = 147, allied HCPs = 60, social worker = 17, medical staff = 5, Other = 30)	Range of years working with cancer patients: 39% 0–5 years 12% 6–11 years 27% 11–20 years 14% 20+ years 8% missing data Received previous training in supporting families with parental cancer: 9%	30–45 min. session Face-to-face 35 trainings of 3–5 participants	fair
Turner et al., 2009 Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention	Australia	Quasi-experimental Pre-Post Design	Educational intervention with self-directed learning manual + Communication skills training workshop	Specific CST to provide supportive care for patients with advanced cancer who have dependent children	Oncology Nurses	32	94% female Age in years: Mean 39.7 (SD 10.4) Marital status: 60% married, 22% single, 9% divorced; Years in oncology: Median 9 (range 0.5–25) Current serious illness in family member: 34% Experiences bereavement of first degree relative: 51%	1-day face-to-face 5 trainings of 5–8 participants	good

(*Continued*)

Table 3. (Continued)

Author, Year Title	Country	Design	Name of CST	Child- or family-specific module	Participants (HCPs)	N of participants	Participants characteristics	CST duration, setting, group size, number of sessions	Quality assessment NIH score
Wittenberg et al., 2020 Caring for Family Caregivers: a Pilot Test of an Online COMFORT ™ SM Communication Training Module for Undergraduate Nursing Students	USA	Quasi-experimental Pre-Post Design	adapted Module F of COMFORT	Adapted Family module: e.g., Family Communication Patterns, the Four Family Caregiver Types and Strategies for communicating effectively with each type	Undergraduate bachelorette students	128	75.6% female Mean age in year: 24.51 75.6% female 31.5% Caucasian, 13.4%, multi-racial, 12.6% African-American English-speaking: 82.7% 1st year students: 7.1% 2nd year students: 22% 3rd year students: 40.9% 4th year students: 18.1%	1-hour online course Participants per training = NR	fair
Wittenberg et al., 2021 [37] Sharing COMFORT Communication Training With Healthcare Professionals in Nairobi, Kenya: A Pilot Webinar Series	Kenya	Quasi-experimental Pre-Post Design	Adapted COMFORT curriculum for a Webinar-Based Training including the 3 of COMFORT's modules: C-Connect, O-Options, F-Family caregivers;	Adapted Family module with following objectives: define family communication patterns; identify differences among family caregiver types; demonstrate awareness of family caregiver communication patterns;	HCPs in Nairobi, Kenya	94 in pre-training survey only (physicians = 52, nurses = 24, other HCPs = 18) 12 completed 3-part webinar series and post-survey (physicians = 6, nurses = 4, other = 2)	Working experience = on average 10 years 88.3% reported having daily communication with patients, 5.3% communicated 3x a week, 2.1% only weekly with patients, 4.3% communicated less than weekly	3x 1-hour webinar series	poor

CST–Communication skills training; HCPs–Healthcare professionals; NIH score–National Institutes of Health (NIH) quality assessment tool for pre-post studies without control group; USA–United States of America; COMSKIL program was developed by Kissane et al. at the Memorial-Sloan-Kettering Cancer Center (MSKCC) in the USA; NR–Not Reported; COMFORT Communication Curriculum developed by Elaine Wittenberg, PhD and Joy Goldsmith, PhD originally as a 2-day face-to-face training for the palliative care setting.

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Table 4. Characteristics of communication skills training interventions.

Author(s), year	Development/Background & pilot-tested	Content	Teaching strategies	Evaluation (Outcomes, measures and time points)	Main results*
Banerjee et al., 2017	• A curriculum development committee identified three CST topics for nurses (communication of empathy with patients and family, discussion of death, dying, and end-of-life goals of care; navigating through difficult family interactions); • qualitative online survey for nurses assessing common communication challenges in the previous defined CST topics • following literature and conceptual and methodological approach of the Comskil conceptual model and Comskil Training programme for oncologists Pilot-tested: NR	*Comskil training program* *Introductory lecture;* *Three 2-h modules*, each including: • a 30-min presentation on theoretical background, recommended communication approach and video display with simulated patient • 90-min small group role play exercises with simulated patients (3 participants) *Content of the modules*: 1. Responding empathically to patients 2. Discussing death, dying and end-of-life goals of care 3. Responding to challenging interactions with families *Additional material*: Each participant received printed booklet on each module	Presentation, Videos incl. simulated patients, written booklet for each module; facilitator-led small group role play sessions with simulated patients incl. reflections and feedback sessions from peers and facilitator, video playback; Facilitators and their professional background: Role-play sessions: facilitated by communication skills specialists (faculty, interventionists, and researches specialized in CSTs) and a specialty-specific nurse (also trained in facilitation). For lectures and presentations = NR	a.) *Program evaluation* with a paper-pencil survey assessing • post-training attitudes regarding learned skills and application (6 items, 5-point Likert scale); • effectiveness of curricula activities in each module including didactic teaching, videos, role play exercises (4 items, 3-point Likert scale); b.) *Participant learning* with • Self-reported self-efficacy retrospective pre-post measure (2 questions per module) • demonstration of skills pre- versus post-training SPAs using an 8-min video recorded interaction between nurse and a simulated patient Follow-up: none Development and Evaluation: based on Kirkpatrick model, adapted to training model; assumption of self-developed tools;	*a.) Program evaluation*: • Training was rated favorably, 90% of nurses agreed or strongly agreed with 5 of 6 learning items; • >80% rated each module as aiding in learning;*b.) Participant learning:*• Overall participants' self-reported self-efficacy significantly improved between retrospective pre- and post-training assessment [$p < .001$], specifically in responding empathically [$p < .001$], discussing death and dying and end-of-life goals of care [$p < .001$], and responding to challenging interactions with families [$p < .001$]; • demonstrated significant improvements over all skills in pre- and post-training assessment [$p < .001$], specifally in several empathetic communication skills [$p < .001$], a skill on clarifying [$p < .001$]s, a skill on summarizing [$p < .05$]. No significant change was observed in the overall areas of agenda setting skills, information organization skills or checking skills.
Cannity et al., 2021	• based on needs assessment of communication challenges for oncology nurses (Banjeree et al 2016) • additional consultation with experts in the field of nursing and communication Pilot-tested: NR	*Comskil training program* One day, three-topic workshop. *Three modules*, each including: • a 30-min presentation on theoretical background, recommended communication approach and video display with simulated patient • 90-min small group role play exercises with simulated patients and clinical vignettes (3 participants), if possible, based on workplace setting (e.g. urgent care) *Content of the 3 modules*: 1. Responding empathically to patients 2. Discussing death, dying and end-of-life goals of care 3. Responding to challenging interactions with families Each participant received printed booklet on each module	Presentation with goals of each module, current literature on the skills, specific techniques to be used, videos demonstrating techniques, role play incl. simulated patients, video-feedback and pre-post SPAs; written booklet for each module; Facilitators and their professional background: Role-play sessions: facilitated by communication skills specialists (faculty, interventionists, and researches specialized in CSTs) and a specialty-specific nurse (also trained in facilitation). For lectures and presentations = NR	a.) Perception of course effectiveness with a paper-pencil survey assessing • Self-reported effectiveness and applicability of skills taught (8 items, 5-point Likert scale); • Rating of specific components aided learning (didactic teaching, videos, role play exercises, 3 items, 3-point Likert scale); b.) Participant learning with • Self-reported pre- and post-training confidence in the specific communication skills (1 pre-, 2 post-training items, 5-point Likert scale); • demonstration of skills pre- versus post-training SPAs using an 8-min video recorded interaction between student and a simulated patient including clinical vignettes developed by nursing experts; coding by two independent blinded raters with Comskil coding system developed by Bylund and colleagues (2011). Follow-up: none Development and Evaluation: based on Kirkpatrick model, but as efficacy study focus on level 1 (reaction of participants to program) and level 2 (evaluation of participants' learning)	*a.) Course effectiveness*: • 90% endorsing engagement or strong agreement with course efficacy overall; • 90% agreed or strongly agreed module 1 and 2 were useful • For module 2, 90% found skills learned useful • 90% of participants reported techniques applied somewhat or strongly helpful in learning; *b.) Participant learning* • Overall participants' confidence significantly improved between pre- and post-training assessment across all three domains [$p < .01$]; Communication skill usage significantly increased between pre- and post-training [$p < .001$];

(*Continued*)

Table 4. (Continued)

Author(s), year	Development/Background & pilot-tested	Content	Teaching strategies	Evaluation (Outcomes, measures and time points)	Main results*
Cronin & Finn, 2017	Synthesized COMFORT communication curriculum from Wittenberg-Lyles et al. 2010, 2014; not further specified. Pilot-tested: NR	COMFORT: **C** communication: Narrative clinical practice, task and relational communication **O** orientation and opportunity: Health literacy, cultural support **M** mindfulness: Remaining present in the moment, adapting to change; **F** family: incorporating family into plans of care, understanding characteristics of various caregivers **O** openings: Recognizing opportunities for discussion, engagement in moments of stress/tension **R** relating: Exploring uncertainty and building trust with patient/families **T** team: Facilitating team meetings, improving communication and interdisciplinary collaboration Taught by 2 instructors, with introduction and description of each of the 7 COMFORT components followed by questions and clarification (approx. 2 hours); intermittently using role playing and videos, exercise on plain language (approx. 1 hour total); discussions and exchange (1 hour);	Power-point lectures describing each of the COMFORT components; videos and role-playing to enhance learning; firsthand videos accounts from an oncology patient sharing his interactions and experiences with viewers; small-group discussions to share personal stories and experiences; exercises on importance of plain language; Facilitators and their professional background: 2 nursing oncology practice specialists	*Precourse-postcourse surveys (2 weeks after attending course)* *Program Evaluation*: quality of the program, satisfaction of learners and whether objectives met; *Participant learning with pre-post survey*: a.) Communication Skills Attitude Scale (CSAS, 26 items, 5-point Likert scale) assessing attitudes toward learning communication skills; b.) Perceived Importance of Medical Communication (PIMC, 12 items, 5-point Likert scale) assessing attitudes towards importance of medical education adapted to fit nursing; c.) Caring Efficacy Scale (CES, 30 items, 6-point Likert scale), assessing nurses' self-perception of competency in nursing practice; Follow-up: none Development: Mix of validated questionnaires (for participants learning, slightly adapted to fit nursing) and self-developed questions for program evaluation;	*Program Evaluation*: overall positive response, some preferred longer course to continue dialogues and discussions regarding their experiences communicating with patients, families and teams. *Participant learning* No statistically significant changes in pre- to post-course measurement, but majority of results (64%) indicate increase of mean scores: a.) CSAS: 86% improvement in nurses' attitudes toward learning communication skills; b.) PIMC: 75% improvement in perceived importance c.) CES: 43% improvement in perceived competencies
Fuoto & Turner, 2019	Synthesized COMFORT communication curriculum from Wittenberg-Lyles et al. 2010, 2015; not further specified. Pilot-tested: NR	COMFORT principles; within role play exercises each nurse was given the opportunity to be the patient, family and the nurse; after each role play a debriefing was held to discuss lessons learned and reinforce how to use COMFORT to guide communication	Lecture and group discussions; role play exercises with peer group feedback and discussions afterwards; COMFORT card for badge holder and posters in staff break rooms and bathrooms; Facilitators and their professional background: NR	Between subject's pre-post design 3 months before implementation and 3 months after implementation; a.) *Demographic survey* (6 items) b.) *Communication confidence survey* (5 items, 4-point Likert scale) c.) *Communication satisfaction survey*–measuring perceived satisfaction during experiences of EOL communication (4 items, 5-point Likert scale) d.) *2 short answer questions* (self-developed) only at 3-month follow-up to measure *changes in daily practice and communication* since participation; e.) *Patient-family satisfaction with EOL care* (FEPC, 39 question survey but only 18 used for the study)–a post death survey 6-weeks after the death of a patient; Follow-up: 3-months post participation only for *d.)* Development: two tools (b, c) developed by others, but not validated; one tool validated, but adjusted questionnaires (FEPC), one self-developed tool (d);	b.) *Communication confidence*: statistically significant increases in confidence in overall ability to communicate in difficult conversations across the three time points [$p = .002$]; in competence communicating with families in crisis [$p < .001$], in competence managing emotional needs at EOL [$p < .001$], competence managing conflicts [$p < .001$] and in overall competence communicating in difficult EOL situations [$p < .001$]; c.) *Communication satisfaction*: statistically significant increases in satisfaction with overall ability to communicate in difficult conversations across the three time points [$p < .001$]; in satisfaction managing emotional needs at EOL [$p < .001$], in managing conflict and in overall satisfaction communicating in difficult EOL situations [$p < .001$]. d.) *changes in daily practice*: three themes emerged on COMFORT impact on daily practice: increased confidence, preparation and increased awareness; *changes in communication practice*: six themes = increased confidence, communication, mindfulness, family, orientation, and no change; most reported using the model regularly, some reported it existed already in their practice; e.) *Patient-family satisfaction with EOL care* (n = 50 respondents, 23 precourse, 27 postcourse): no significant difference in score before versus after training, although baseline results were generally high and most respondents rated palliative services with the best possible response.

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Table 4. (Continued)

Author(s), year	Development/Background & pilot-tested	Content	Teaching strategies	Evaluation (Outcomes, measures and time points)	Main results*
Quinn et al., 2008	Developed by • evidence from a literature review (not specified); • collective clinical experience of project team • Australian Standards for Palliative Care • input from an expert panel/ advisory group (n = 13) comprising academics, policy makers, clinicians, caregiver representatives representing clinical and academic palliative care fields; Pilot-tested: NR	Program Day 1: 1. Clinical and public health approaches to palliative care 2. Decision making in palliative care: ethical and legal challenges 3. Assessing and responding to spiritual and cultural issues 4. Family centered care 5. Grief, loss, and bereavement Program Day 2: 6. Communicating with patients, families and colleagues 7. Palliative care and nonmalignant disease 8. (doctors and nurses) frequently asked questions OR Multidisciplinary Team- does it work? (allied health clinicians) 9. Care of an imminently dying person and their family Panel discussion	Didactic, question and answer sessions, workshops and panel/case discussions; Resources, appropriate to each session, including relevant reading materials, websites, and reference lists were provided to each participant. Closing session in form of a panel discussion including local palliative care services. Facilitators and their professional background: Sessions presented by specialist palliative care clinicians from a range of disciplines, but not further specified;	a.) *Demographic survey* b.) *Generic palliative care questionnaire*– measuring participant perception related to importance, knowledge, and confidence with palliative care in eight areas (self-developed, 61 items on a 5-point Likert scale), pre-and post-program participation + additionally 1-month follow-up c.) *Session Evaluation Questionnaire*– measuring any benefit to level of interest, extent of new information learned and perceived usefulness of each session (3 questions, 4-point Likert scale) d.) *Total program evaluation* (self-developed, qualitative evaluation) after the program with open-ended questions to encourage participants to provide comments not captured by questionnaire (e.g. strength and weaknesses of the program, ongoing learning needs, and identify challenges in implementing change in their workplace) *changes in daily practice and communication* since participation;e.) *Focus group 1-month follow-up (with n = 8 participants)*: aimed to explore the organization, appropriateness and relevance of the program content to practice, recommendations for improvements and possible concerns or issues by participants Follow-up: 1-month follow-up for *b.)* Development: self-developed, not validated tools;	b.) Multivariate effects were found within groups for time [$p < .0001$], showing significant differences with positive effects on importance, knowledge, and confidence in all eight areas from pre- to post-test, with stronger association for knowledge and confidence [$p < .001$], weaker for importance [$p < .01$—$p < .05$] (pretest scores were already fairly high though), response rate was ≈70%; Follow-up questionnaire had only a response rate of 17%; no additional analyses repeated; c.) Overall, session evaluations were positive, Session 6 and 7 were scored highest. d.) Reported strengths were passionate conviction of excellent speakers, well-balanced coverage of the program, take-home resources were highly valued, time allowed for questions. Reported suggestions for improvements were including more group sharing and participation, maintaining interest despite participant fatigue towards the end of each day; e.) results: strong recommendation to colleagues, applicable to daily practice, improved motivation and confidence to change own practice.
Semple et al., 2017	Content was derived from experiences of an expert team, which included an oncology nurse specialist, a professor in cancer care, a cancer nurse researcher, a family support coordinator and a parent; additionally, findings of empirical studies; Pilot-tested: NR	Education sessions on: • the importance of communicating with children about their parent's cancer • difficulties reported by oncology professionals when working with parents; • the essential need to support parents diagnosed with cancer; • how to start the conversation with parents; • guiding principles when talking to children about parental cancer • Finding the words, using a case example • Helpful tips when supporting families affected by parental cancer Discussion round to reflect and share experiences	Delivery incorporated aspects of advanced communication skills training and learning methods to encourage reflection by participants and integration of case studies. Facilitators and their professional background: Two facilitators: one being a family support coordinator for Cancer Focus Northern Ireland, a cancer charity that provides special support to families with parental cancer; the other being an experienced clinical nurse specialist leading a program of work on family centered cancer care;	Self-generated survey including single items and a free text section for comments; a.) Demographic background b.) Perceived confidence and competence to communicate with parents about parental cancer (three clinical scenario-based single item questions, 10-point Likert scale); *pre-post participation;* c.) Perceived increase of knowledge, recommendation to colleagues, influence on daily practice post-participation (three single item questions, 10-point Likert scale) d.) Free-text section Follow-up: noneDevelopment: self-developed, development by experienced researchers and extensively described and each item was reviewed and refined for content and face validity, pilot-tested with a small group of HCPs;	b.) significant improvements in participants' perceived confidence and competence after the educational session on all three clinical scenario-based questions [$p < .001$]; improvements did not differ by professional background, years of experience, or having received formal training before; there were some significant group differences at baseline (nursing students vs. medical staff), however all participants' confidence and competence increased in a similar way; c.) participants perceived the education session increased their knowledge, that it would influence their daily practice and they would recommend it to colleagues; only statistically significance difference between mean scores for staff nurses compared to nursing students on knowledge gained and recommendation of training to others [$p < .001$]; statistically significant lower mean scores for allied health professionals influence on daily practice [$p < .001$]. d.) themes within free text sections were increased knowledge, useful for practice, optimal delivery to enhance learning, desire for more in-depth training; overall very positive responses and feedback.

(*Continued*)

Table 4. (Continued)

Author(s), year	Development/Background & pilot-tested	Content	Teaching strategies	Evaluation (Outcomes, measures and time points)	Main results*
Turner et al., 2009	• literature review on key issues: the impact of advanced cancer on parents and children; strategies to promote adjustment; communication with patients with cancer, staff stress, burnout.and resilience research • Focus groups with oncology nurses to identify educational needs • Expert panel (n = 6 nurses with a national profile in nursing education and service delivery) reviewed the manual, documenting their opinions about the relevance, style and content of each section of the manual, noting if any important topics were missing; Pilot-tested: only the manual by expert panel	Self-directed educational manual including three modules: overview of evidence about communication in oncology, with special reference to parents with advanced cancer; Needs of children of parents with cancer, Issues for parents with advanced cancer; Interventions to promote adjustment in children; prompts and suggestions to be used in response to specific challenges, such as parents who express anger, guilt about their illness. Communication skill training workshop including overview of the evidence about communication in oncology with special reference to parents with advanced cancer, after which participants' developed role-plays and participated in these.	Presentations, group work to develop role-plays (participants developed role-plays on their own), participate in role-plays, constructive feedback for role-plays Participants had to define their own learning needs, participate in role-plays and receive constructive feedback. Facilitators and their professional background: NR	a.) Demographic background b.) Measures of burnout and psychological morbidity: Maslach Burnout Inventory (MBI) General Health Questionnaire 28 (GHQ) c.) Measures of perceived stress (4 items), confidence (5 items) and attitudes (5 items; all self-developed measure, pilot-tested: 5-point Likert scale) d.) Assessment of knowledge–two clinical vignettes e.) Assessment of skills–simulated 5-min video-taped interviews with simulated patient incl. quality rating (General Interactional skills) and responses to Scripted Cues f.) Subgroup Analyses g.) Acceptability survey 6-months after workshop participation (usefulness of components of the educational manual on a 5-point Likert scale; description of own emotional responses to the workshop, impact of the training on clinical practice) Follow-up: 6-months after completion of post-questionnaire Development: Mix of validated questionnaires (MBI, GHQ) and self-developed tools, being developed with literature review and results of focus groups (c) and partly pilot-tested (c)	b.) GHQ: significant reduction in Somatic subscale scores over time [p = .02]; c.) After participation nurses were significantly more likely to report taking an active role in 'caring for myself emotionally and spiritually'. Significant increases in confidence about ability to provide support [p < .001], and information [p < .001], and to raise discussions about emotional issues with parents [p < .001]; d.) Over time there were significant reductions in pragmatic responses to the two vignettes [p = .001; p = .002], recommendation of referral [p = .02; p = .03], and significant increases in promoting coping responses [p = .02; p≤.001]. e.) Comparisons revealed significant improvements in all categories of communication [p≤.001 till p = .002] except for responses to Unscripted Emotional Cues. Significant reduction in frequency of blocking responses [p≤.001]. f.) Small sample size, therefore limited number of subgroup analyses conducted. Nurses scoring high on Emotional Exhaustion at recruitment were significantly more likely to have low confidence in ability to provide support for parents [p = .015], and a low degree of initiative in self-care strategies [p = .013]. Nurses aged ≤ 40 years had significantly higher worries about what to say when patients were distressed [p = .041], but there were no other significant associations between younger age and confidence or attitudes. Nurses with previous experienced bereavement were significantly less likely to score as 'cases' on the GHQ [p = .012]. g.) Response of N = 17 nurses only. Training was generally acceptable. Qualitative analysis of responses revealed 2 dominant themes: increased confidence and recognition about support does not involve solving patient's problems.

(*Continued*)

Table 4. (Continued)

Author(s), year	Development/Background & pilot-tested	Content	Teaching strategies	Evaluation (Outcomes, measures and time points)	Main results*
Wittenberg et al. 2020	• Modified and developed based on Family Caregiver Communication Typology (FFCT), grounded in communication theory and included evidence-based communication skills. • Face validity to typology was given by feedback from 2-day COMFORT Communication training course participating nurses. • Revision of module by five nurse educators working range of institutions (during early development phase, and after module completion) including open feedback on content, design and sequence of materials. • An instructional education designer proficient in online learning platforms and educational theory then designed the online format of the educational material. Pilot-tested: yes, with five nurse educators	Modified F module COMFORT including three learning outcomes (knowing the four different caregiver communication types, describing the family communication patterns for each caregiver type, responding to each given scenario in a manner responsive to different caregiver types) within 9 Sections	Online training including videos, case study examples, reflection and assessment exercises, feedback from the instructor on participants' submitted reflection. Included all of the American Association of College of Nurses curriculum guidelines required for baccalaureate nurses including practice-based learning and improvement, evidence-based practice, interprofessional and interpersonal communication skills, professionalism, and system-based practice Facilitators and their professional background: N/A	Pre-post survey immediately prior to and immediately after participation assessing: a.) Demographic survey (baseline only) b.) attitude (2 items) c.) knowledge (5 items) d.) behavior (3 items) e.) open-ended questions with section 5–8 capturing knowledge and behavior (3 questions) Follow-up: none Development: developed by research team based on prior communication research;	b.)—d.) significant statistical increase in the scores from pre-test to post-test [$p < .001$], therefore online module had an effect on nursing student attitude, knowledge, and behavior for communicating with caregivers (with first- and fourth-year students showing biggest increase across these 3 topics. e.) majority of responses correctly described the family communication pattern presented in the case study: Descriptions of their behavior with each caregiver type in response to a case study scenario revealed that student mastery of content (level 2 or higher) ranged from 40% –56% across caregiver types. Responses classified at levels 2–4 demonstrate fluidity of knowledge skills in addition to goal complexity and mastery.
Wittenberg et al. 2021	3-part communication training webinar series built and offered based on COMFORT Curriculum, adapted by reviewing literature on communication challenges in Nairobi area/Africa; Pilot-tested: NR	Adapted COMFORT curriculum for a Webinar-Based Training including 3 of COMFORT's 7 modules: C-Connect, O-Options, F-Family caregivers; applied as a 3-part webinar series;	Webinar included chat feature, recording, slide decks, learning objectives, interactive polling, and application of exercises for audience members to practice new communication skills	Online survey assessing: a.) Demographics b.) Previous educational training on specific communication topics c.) Pre-post assessment of adapted (?) Comfort with Communication in Palliative and End of Life Care (C-COPE) (15 items reported, 5-point Likert scale d.) Survey on education program (3 items for each webinar, 5-point Likert scale) and overall course evaluation (? Items, 5-point Likert scale) Follow-up: none Development: NR and not possible to follow adapted C-COPE assessment;	c.) significant change in level of perceived communication comfort in 75% of participants (N = 9, p-value not reported); d.) overall webinars received high evaluation (M 4.5 from 5), Module F on Family Caregivers ranking highest (M 4.65 from 5)

* only significant findings will be reported due to clarity of table

CST = Communication skills training; Comskil program: developed by Kissane et al. at the Memorial-Sloan-Kettering Cancer Center (MSKCC) in the USA; NR = not reported; SPAs: standardized patient assessments; COMFORT ™ SM Communication Curriculum developed by Elaine Wittenberg, PhD and Joy Goldsmith, PhD originally as a 2-day face-to-face training for the palliative care setting; EOL: end of life; HCPs = Healthcare professionals; NA = not applicable/applied.

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COMFORT curriculum without further information or explanation for possible variations in content of their CST within their reports. Fuoto et al. [34] described their module as "Family module: support caregiver involvement and understanding" and Wittenberg et al. (2021) [37] "F-Family caregivers".

Didactic techniques/materials

All included studies combined various didactic techniques and materials within their training program. Role-play exercises with regular feedback were part of five studies [23, 31–34], role-play exercises with simulated patients were incorporated in three studies [23, 31, 32]. All studies but the study using the e-learning [35] gave some kind of presentation (e.g., power-point introduction on training or overview of communication skills). Discussion rounds were part of the training in four studies [33, 34, 36, 38] and videos e.g., to illustrate key skills or family needs included four studies [31–33, 35]. Moreover, various studies used written material in form of manuals [23, 36], booklets [31, 32] or pocket-cards [34]. Five studies reported on professional background of CST facilitators [31–33, 36, 38], which varied greatly between studies (for details see Table 4).

Outcome measurement

Included studies varied considerably in defined outcomes and applied instruments (e.g., number of items, scales, description of adapted instruments). Most instruments have been self-developed without validation (see Table 4 for details). Two studies applied Kirkpatrick's framework [29] for training evaluation, focusing on the first two levels: participant's reaction and learning [31, 32].

Participants' satisfaction with the CST was assessed post-training participation. Five studies evaluated satisfaction using quantitative evaluation surveys [31–33, 36, 37] and two qualitative methods (e.g., open-ended questions [35]; focus groups [36]). Some studies assessed overall satisfaction with CST [33, 36, 37], others assessed satisfaction with individual sessions/modules [31, 32, 37, 38]. Overall, assessment of participants' satisfaction varied considerably.

Majority of studies (n = 8) included a pre-post participation assessment of ***self-efficacy and/or perceived confidence in communication competencies*** [23, 31–34, 36–38]. Three studies analyzed change of HCPs' ***attitudes*** [23, 33, 35] (e.g., towards the importance of learned skills [33]), three studies analyzed change of HCPs' self-perceived ***communication behavior*** in daily practice [34, 35, 38] and three ***observed communication skills*** assessed through simulated patient assessments (SPAs) [23, 31, 32] pre-post training participation. Two studies measured change in ***perceived importance*** of communication [33, 36]. Four studies assessed change of ***knowledge*** how to support parents and families [23, 35, 36, 38], e.g., knowledge on palliative care [36] or retrospectively perceived increase of knowledge on supportive needs of parents and families [38]. HCPs' ***general health*** (burnout and perceived stress as secondary outcomes) [23] and ***patient-reported outcomes*** [34] (adapted version of the patient-family satisfaction with End-of-Live care survey (FEPC), a post-death survey for relatives originally developed by the Natioanl Hospice and Palliatve care Organization in Virginia, USA, however not available) were each reported in one study.

Evaluation of CST following Kirkpatrick's framework for training evaluation

Reaction–Participant's satisfaction with the training. Overall, participants' reaction to CST was predominantly positive. Participants rated the trainings beneficial for applying it to their daily practice [36, 38], to increase their confidence [23] and would recommend it to their colleagues

[36, 38]. Reported suggestions were e.g., increasing group sharing exercises [36] or discussion/exchange rounds to share their experiences with affected families [33].

Learning–Effects on participant's communication confidence, attitudes and knowledge. Statistically significant improvement on participants' self-reported ***self-efficacy in communication competencies*** were found in seven studies [23, 31, 32, 34, 36–38] with considerable variation in defined outcomes and applied instruments (see Table 4 for details). One study did not report detailed statistic parameters [37]. Two of the three studies assessing participants' ***attitudes*** reported significant improvements over time [23, 35]. Only one of the two studies assessing ***perceived importance*** of communication found significant improvements over time [36]. Regarding ***knowledge***, three studies reported significant improvements over time [23, 35, 36], with one study missing clear and detailed statistic parameters [35].

Behavior–Participant's change in behavior. Of the three studies assessing daily ***communication behavior***, only one study reported on significant changes, but did not provide statistic parameters [35]. Semple et al. assessed change of communication behavior only at post-participation without comparison over time [38] and Fuoto et al. with an open-answer format only [36]. Significant changes in ***observed communication skills*** were found in three studies. Banerjee et al. and Cannity et al. reported significant improvements for overall skills using both the same Comskil coding manual [31, 32], Turner et al. for five of their six categories on measuring General Interaction skills and responses to Scripted Cues [23].

Results–other improvements in patient-oriented healthcare. One study assessed participants' ***general health*** using the General Health Questionnaire 28 (GHQ), the level of perceived stress (self-administered) and burnout with the Maslach Burnout Inventory (MBI) [23]. There were no significant changes in stress and burnout or level of perceived stress. Significant decrease in the somatic subscale of the GHQ was reported. Regarding the patient-reported outcomes measuring patient-family satisfaction with care no significant differences between pre- and post-training scores were found [34].

Both studies specifically focusing their CST to provide support for cancer patients parenting minor children found significant changes within the pre-and post training assessment for multiple outcomes [23, 38] (see Table 4).

Methodological quality assessment

The methodological quality of included studies was rated as "fair" in six [32–36, 38], "poor" in two [31, 37] and "good" in only one included study [23] (see Table 3). None of the included studies reported on a sample size calculation, the statistical methods of two studies were of poor reporting quality [31, 37], the eligibility criteria for participants were only partly or not described in eight studies [23, 31–33, 35, 38], outcome measures were not or only partly reported in all studies, and only two studies reported on consistent delivery of intervention [23, 38].

Discussion

This review aimed to provide an overview of existing CST interventions for HCPs in oncology explicitly addressing child- and parent-specific aspects in adult cancer care. Second, the review aimed to assess reported outcome measures associated with the CST's evaluation. The third aim was to report on CST effectiveness. Since only two studies were identified explicitly reporting on a CST solely focusing on parental cancer, we broadened our focus during the screening process to also include studies reporting on a family-specific module within their CST. Thus, in total, we included nine studies with at least one module on child- or family-specific aspects in communication in cancer care. The seven included studies including a family-specific

module did not provide details what is included (e.g., parental-specific aspects during cancer care). Hence, it remains unclear if and to which extend children as relatives of cancer patients are explicitly addressed. Findings of the present work are consistent with previous research identifying a lack of communication skills trainings in oncological care especially for HCPs caring for patients experiencing additional burden and needs [41].

In our included studies, nurses represented a large proportion of participants with six studies including nurses only [23, 31–35] and two studies mainly including nurses [36, 38]. This is not surprising as one frequently evaluated CST is the COMFORT curriculum explicitly developed for nurses [40]. As nurses spend a considerable amount of their working time caring for patients, developing a close relationship with their patients and relatives [42], they are often confronted with patient's specific needs and provide emotional support [43]. Additionally, shortage of nursing staff globally and a continuous physically and emotionally draining job [23, 44] increase the need to enhance effective communication with patients and their families to reduce stress experience and emotional exhaustion in nursing profession [43, 45, 46].

Physicians usually are the key contact and person of trust for patients during cancer care [47]. Therefore, they can act as gatekeepers for additional support according to child- and family-related needs. However, in the included studies only few physicians participated.

Studies on child- and parental-related issues report lack of knowledge and specific communication skills as well as perceived limited competence on parental issues in clinicians in cancer care [10, 11, 21]. This strongly indicates a need for 1) specifically developed training programs for physicians and oncologists incorporating child- and parent-specific aspects or 2) optimization of access to existing interventions to improve participation of physicians, e.g., by including incentives or adapting trainings to their specific needs and working schedule.

Six of the included studies found significant improvements in either self-efficacy and/or confidence, behavior and knowledge for general communication skills, two additional studies for specific communication aspects in parental cancer. This implies that CSTs are a promising approach to improve HCPs communication skills including specific skills on parental cancer and support building a bridge to communicate effectively with affected parents and their families. This implication is supported by previous research, indicating increased self-efficacy, knowledge and skills [48] will in turn improve (a) HCP's communication behavior, (b) HCP's satisfaction with communication and their mental well-being health (e.g., reduced emotional burn-out) [25], and (c) outcomes for patients and their families (e.g., reduced stress and feelings of anxiety, improved satisfaction with care [26, 49]). However, findings are not generalizable due to small sample sizes in most studies included in this review and only two included studies applying a specific CST on parental cancer.

The overall methodological quality of included studies was fair to poor. Applied outcome measures varied considerably and psychometric properties of measures were insufficient. However, validated and reliable tools assessing specific communication skills and behavior in child- and family-specific aspects in cancer care are rare [23, 38, 50]. Hence, there is a need for rigorously developed and psychometrically sound instruments. Moreover, objective simulated patient assessments (SPAs) should be included in future studies as they are the gold standard for evaluation of CSTs [51, 52]. Clinical case vignettes, as used in one included study [23], have been found to be comparable to SPAs [52]. However, development of vignettes should be standardized and follow current recommendations [53].

Study limitations

This study has several limitations. First, this systematic review focused on CSTs with a specific module on child- or family specific aspects in cancer care. Though our search strategy was

extensive, the articles reviewed may not represent all CSTs with such specific modules in cancer care given the restrictions of search terms used, databases searched and requirements for English- or German-language due to language restrictions of the authors. However, by including a thorough secondary literature search, additional relevant CSTs were included. Second, as included studies varied considerably in e.g., CST content and outcome assessment and tools used, comparison of CSTs and their quality of evidence is difficult and generalizability is impeded. Additionally, based on our quality assessment, only one study with good methodology design was included.

Clinical implications

Overall, implication for future research is to develop a structured and theory-based communication skills intervention for HCPs in oncology to improve family-centered cancer care, specifically when a parent has cancer [38, 43]. Future studies should develop specific trainings to enhance HCPs communication skills, knowledge and self-efficacy to address child- and family-specific aspects when a parent has cancer. Also, these studies should provide an evaluation using state of the art methodology (e.g., including a control group thorough outcome assessment with validated, and pilot-tested outcome measurements based on e.g., Kirkpatrick's model of evaluation) [29, 50]. Additionally, newly developed interventions should specifically address physicians and oncologists and if possible be adapted to their needs to increase participation of this specific HCP group. Existing studies including a family-specific module should provide further detail on the topic of "family communication", e.g., if minor children are included as family members [29, 50].

Conclusion

This systematic review gives an overview of existing CSTs for HCPs on parenthood and cancer. Despite a high need for a specific CST to improve HCP's communication skills regarding parental cancer, only two CSTs focusing on parental cancer were identified, the remaining seven studies only included a brief module on family communication. The quality of evidence for included studies remains insufficient. Due to the lack of specific CSTs and poor or only fair quality of the included studies, further CSTs on aspects of parental cancer should be developed and evaluated rigorously.

Supporting information

S1 Checklist. PRISMA 2009 checklist.
(DOC)

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References

1. Dencker A, Murray SA, Mason B, Rix BA, Bøge P, Tjørnhøj-Thomsen T. Disrupted biographies and balancing identities: A qualitative study of cancer patients' communication with healthcare professionals about dependent children. European journal of cancer care. 2019; 28(2):e12991. https://doi.org/10.1111/ecc.12991 PMID: 30628750
2. Hailey CE, Yopp JM, Deal AM, Mayer DK, Hanson LC, Grunfeld G, et al. Communication with children about a parent's advanced cancer and measures of parental anxiety and depression: a cross-sectional mixed-methods study. Support Care Cancer. 2018; 26(1):287–95. https://doi.org/10.1007/s00520-017-3847-9 PMID: 28785863
3. Inhestern L, Johannsen LM, Bergelt C. Families Affected by Parental Cancer: Quality of Life, Impact on Children and Psychosocial Care Needs. Frontiers in psychiatry. 2021;12. https://doi.org/10.3389/fpsyt.2021.765327 PMID: 34858234
4. Nilsson ME, Maciejewski PK, Zhang B, Wright AA, Trice ED, Muriel AC, et al. Mental health, treatment preferences, advance care planning, location, and quality of death in advanced cancer patients with dependent children. Cancer. 2009; 115(2):399–409. https://doi.org/10.1002/cncr.24002 PMID: 19110677
5. Schiena E, Hocking A, Joubert L, Wiseman F, Blaschke S. An Exploratory Needs Analysis of Parents Diagnosed with Cancer. Australian Social Work. 2019; 72(3):325–35.
6. Fearnley R, Boland JW. Parental Life-Limiting Illness: What Do We Tell the Children? Healthcare (Basel). 2019; 7(1). https://doi.org/10.3390/healthcare7010047 PMID: 30897857
7. Helseth S, Ulfsaet N. Parenting experiences during cancer. J Adv Nurs. 2005; 52(1):38–46. https://doi.org/10.1111/j.1365-2648.2005.03562.x PMID: 16149979
8. Konings S, McDonald FEJ, Patterson P. Supporting parents impacted by cancer: Development of an informational booklet for parents with cancer who have adolescent and young adult children. Psychooncology. 2020; 29(12):2101–4. https://doi.org/10.1002/pon.5475 PMID: 32658378
9. Dalton L, Rapa E, Ziebland S, Rochat T, Kelly B, Hanington L, et al. Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent. Lancet (London, England). 2019; 393(10176):1164–76.
10. Fearnley R, Boland JW. Communication and support from health-care professionals to families, with dependent children, following the diagnosis of parental life-limiting illness: A systematic review. Palliative Medicine. 2017; 31(3):212–22. https://doi.org/10.1177/0269216316655736 PMID: 27383635
11. Heynemann S, Philip J, McLachlan SA. An exploration of the perceptions, experience and practice of cancer clinicians in caring for patients with cancer who are also parents of dependent-age children. Support Care in Cancer. 2021; 29(7):3895–902. https://doi.org/10.1007/s00520-020-05969-x PMID: 33386989
12. Chen R, Fall K, Czene K, Kennedy B, Valdimarsdóttir U, Fang F. Impact of parental cancer on IQ, stress resilience, and physical fitness in young men. Clin Epidemiol. 2018; 10:593–604. https://doi.org/10.2147/CLEP.S152210 PMID: 29872348
13. Forrest G, Plumb C, Ziebland S, Stein A. Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: qualitative study. BMJ (Clinical research ed). 2006; 332(7548):998–1003.
14. Visser A, Huizinga GA, van der Graaf WT, Hoekstra HJ, Hoekstra-Weebers JE. The impact of parental cancer on children and the family: a review of the literature. Cancer Treat Rev. 2004; 30(8):683–94. https://doi.org/10.1016/j.ctrv.2004.06.001 PMID: 15541578
15. Scholl I, Zill JM, Härter M, Dirmaier J. An Integrative Model of Patient-Centeredness–A Systematic Review and Concept Analysis. PLOS ONE. 2014; 9(9):e107828. https://doi.org/10.1371/journal.pone.0107828 PMID: 25229640

16. Byock I. Completing the continuum of cancer care: Integrating life-prolongation and palliation. CA: A Cancer Journal for Clinicians. 2000; 50(2):123–32. https://doi.org/10.3322/canjclin.50.2.123 PMID: 10870488

17. Harris J, Bowen DJ, Badr H, Hannon P, Hay J, Regan Sterba K. Family communication during the cancer experience. J Health Commun. 2009; 14 Suppl 1:76–84. https://doi.org/10.1080/10810730902806844 PMID: 19449271

18. Thomson MD, Genderson MW, Siminoff LA. Understanding cancer caregiver burden over time: Dyadic assessments of family cohesion, conflict and communication. Patient Education and Counseling. 2022; 105(6):1545–51. https://doi.org/10.1016/j.pec.2021.10.014 PMID: 34728096

19. Semple CJ, McCance T. Experience of parents with head and neck cancer who are caring for young children. Journal of Advanced Nursing. 2010; 66(6):1280–90. https://doi.org/10.1111/j.1365-2648.2010.05311.x PMID: 20546362

20. Schouten B, Bergs J, Vankrunkelsven P, Hellings J. Healthcare professionals' perspectives on the prevalence, barriers and management of psychosocial issues in cancer care: A mixed methods study. European Journal of Cancer Care. 2019; 28(1):e12936. https://doi.org/10.1111/ecc.12936 PMID: 30298960

21. Dencker A, Rix BA, Bøge P, Tjørnhøj-Thomsen T. A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children. Psychooncology. 2017; 26(12):2162–7. https://doi.org/10.1002/pon.4440 PMID: 28419731

22. Ernst JC, Beierlein V, Romer G, Möller B, Koch U, Bergelt C. Use and need for psychosocial support in cancer patients: a population-based sample of patients with minor children. Cancer. 2013; 119(12):2333–41. https://doi.org/10.1002/cncr.28021 PMID: 23575997

23. Turner J, Clavarino A, Butow P, Yates P, Hargraves M, Connors V, et al. Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention. European Journal of Cancer. 2009; 45(10):1798–806. https://doi.org/10.1016/j.ejca.2009.02.023 PMID: 19329294

24. Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. Cochrane Database of Systematic Reviews (online). 2013; 2013(3):Cd003751. https://doi.org/10.1002/14651858.CD003751.pub3 PMID: 23543521

25. Moore PM, Rivera S, Bravo-Soto GA, Olivares C, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. Cochrane Database of Systematic Reviews. 2018; 7(7):Cd003751. https://doi.org/10.1002/14651858.CD003751.pub4 PMID: 30039853

26. Uitterhoeve RJ, Bensing JM, Grol RP, Demulder PH, T VANA. The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature. European Journal of Cancer Care. 2010; 19(4):442–57.

27. Bos-van den Hoek DW, Visser LNC, Brown RF, Smets EMA, Henselmans I. Communication skills training for healthcare professionals in oncology over the past decade: a systematic review of reviews. Curr Opin Support Palliat Care. 2019; 13(1):33–45. https://doi.org/10.1097/SPC.0000000000000409 PMID: 30562180

28. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ (Clinical research ed). 2021; 372:n71.

29. Kirkpatrick DL, Kirkpatrick JD. Evaluating training programs: the four levels. 3rd ed. San Fransisco: Berrett-Koehler Publication; 2006.

30. NIH. National Heart Lung and Blood Institute. Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group [Internet] Bethesda, MD, USA: NIH National Heart Lung and Blood Institute; 2021[cited 2021 June 3] [Available from: https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools].

31. Banerjee SC, Manna R, Coyle N, Penn S, Gallegos TE, Zaider T, et al. The implementation and evaluation of a communication skills training program for oncology nurses. Translational Behavioral Medicine. 2017; 7(3):615–23. https://doi.org/10.1007/s13142-017-0473-5 PMID: 28211000

32. Cannity KM, Banerjee SC, Hichenberg S, Leon-Nastasi AD, Howell F, Coyle N, et al. Acceptability and efficacy of a communication skills training for nursing students: Building empathy and discussing complex situations. Nurse Education in Practice. 2021; 50:102928. https://doi.org/10.1016/j.nepr.2020.102928 PMID: 33310509

33. Cronin JA, Finn S. Implementing and Evaluating the COMFORT Communication in Palliative Care Curriculum for Oncology Nurses. Journal of Hospice & Palliative Nursing. 2017; 19(2):140–6.

34. Fuoto A, Turner KM. Palliative Care Nursing Communication: An Evaluation of the COMFORT Model. Journal of Hospice & Palliative Nursing. 2019; 21(2):124–30. https://doi.org/10.1097/NJH.0000000000000493 PMID: 30688799

35. Wittenberg E, Goldsmith JV, Williams Y, Lee A. Caring for Family Caregivers: a Pilot Test of an Online COMFORT™ (SM) Communication Training Module for Undergraduate Nursing Students. Journal of Cancer Education. 2020; 35(1):138–43. https://doi.org/10.1007/s13187-018-1452-3 PMID: 30467775

36. Quinn K, Hudson P, Ashby M, Thomas K. "Palliative care: the essentials": evaluation of a multidisciplinary education program. Journal of Palliative Medicine. 2008; 11(8):1122–9. https://doi.org/10.1089/jpm.2008.0044 PMID: 18980453

37. Wittenberg E, Alabere RO, Beltran E, Goldsmith JV, Moledina S. Sharing COMFORT Communication Training With Healthcare Professionals in Nairobi, Kenya: A Pilot Webinar Series. Am J Hosp Palliat Care. 2022; 39(4):421–6. https://doi.org/10.1177/10499091211026673 PMID: 34159800

38. Semple CJ, McCaughan EM, Smith R. How education on managing parental cancer can improve family communication. Cancer Nursing Practice. 2017; 16(5):34–40.

39. Bylund CL, Brown RF, Bialer PA, Levin TT, Lubrano di Ciccone B, Kissane DW. Developing and implementing an advanced communication training program in oncology at a comprehensive cancer center. Journal of Cancer Education. 2011; 26(4):604–11. https://doi.org/10.1007/s13187-011-0226-y PMID: 21541813

40. Wittenberg E, Goldsmith JV, Ragan SL, Parnell TA. Communication in Palliative NursingThe COMFORT Model: The COMFORT Model: Oxford University Press; 2020 2020–01.

41. Hilaire DM. The need for communication skills training in oncology. J Adv Pract Oncol. 2013; 4(3):168–71. https://doi.org/10.6004/jadpro.2013.4.3.4 PMID: 25031996

42. Sivesind D, Parker PA, Cohen L, Demoor C, Bumbaugh M, Throckmorton T, et al. Communicating with patients in cancer care; what areas do nurses find most challenging? Journal of Cancer Education. 2003; 18(4):202–9. https://doi.org/10.1207/s15430154jce1804_7 PMID: 14766330

43. Turner J, Clavarino A, Yates P, Hargraves M, Connors V, Hausmann S. Oncology nurses' perceptions of their supportive care for parents with advanced cancer: challenges and educational needs. Psychooncology. 2007; 16(2):149–57. https://doi.org/10.1002/pon.1106 PMID: 17061311

44. Ehegartner V, Kirschneck M, Frisch D, Schuh A, Kus S. Arbeitsfähigkeit von Pflegekräften in Deutschland–welchen Präventionsbedarf hat das Pflegepersonal: Ergebnisse einer Expertenbefragung. Gesundheitswesen. 2020; 82(05):422–30.

45. Carvajal A, Haraldsdottir E, Kroll T, McCormack B, Errasti-Ibarrondo B, Larkin P. Barriers and facilitators perceived by registered nurses to providing person-centred care at the end of life. A scoping review. International Practice Development Journal. 2019.

46. Adams A, Mannix T, Harrington A. Nurses' communication with families in the intensive care unit - a literature review. Nurs Crit Care. 2017; 22(2):70–80. https://doi.org/10.1111/nicc.12141 PMID: 25583405

47. Götze H, Zenger M, Brähler E, Romer G, Ernst J. Brustkrebspatientinnen mit minderjährigen Kindern–Psychosoziale Belastung und Unterstützungswünsche. Zeitschrift für Psychiatrie, Psychologie und Psychotherapie. 2014; 62(1):55–63.

48. Berg MN, Ngune I, Schofield P, Grech L, Juraskova I, Strasser M, et al. Effectiveness of online communication skills training for cancer and palliative care health professionals: A systematic review. Psychooncology. 2021; 30(9):1405–19. https://doi.org/10.1002/pon.5702 PMID: 33909328

49. Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. European Journal of Cancer. 1999; 35(11):1592–7. https://doi.org/10.1016/s0959-8049(99)00212-9 PMID: 10673967

50. Inhestern L, Frerichs W, Johannsen LM, Bergelt C. Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot study. BMJ Open. 2019; 9(10):e032778. https://doi.org/10.1136/bmjopen-2019-032778 PMID: 31615803

51. Johannsen LM, Frerichs W, Inhestern L, Bergelt C. Assessing competencies of healthcare professionals caring for parents with cancer: The development of an innovative assessment tool. Psychooncology. 2020; 29(10):1670–7. https://doi.org/10.1002/pon.5507 PMID: 32779287

52. Riley AH, Critchlow E, Birkenstock L, Itzoe M, Senter K, Holmes NM, et al. Vignettes as research tools in global health communication: a systematic review of the literature from 2000 to 2020. Journal of Communication in Healthcare. 2021; 14(4):283–92.

53. Evans SC, Roberts MC, Keeley JW, Blossom JB, Amaro CM, Garcia AM, et al. Vignette methodologies for studying clinicians' decision-making: Validity, utility, and application in ICD-11 field studies. Int J Clin Health Psychol. 2015; 15(2):160–70. https://doi.org/10.1016/j.ijchp.2014.12.001 PMID: 30487833

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ORIGINAL ARTICLE

Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study

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Abstract

Objective: Cancer patients parenting minor children face specific burden and supportive needs, which are often not adequately addressed by their healthcare professionals (HCPs), due to a lack of knowledge, self-efficacy and competencies. Therefore, we developed a 3-h intervention enhancing HCPs' competencies in caring for these patients. We pilot-evaluated the intervention's feasibility and efficacy, assuming intervention group participants reveal higher improvements over time compared to non-trained participants.

Methods: We conducted a 3-armed randomized controlled pilot-trial (RCT), comparing face-to-face training (F2F), e-Learning (EL), waitlist-control group with three measurements (baseline, post-training, 3-month follow-up). Primary outcome was the competency to approach child- and family-related themes; secondary outcomes were knowledge, self-efficacy in (specific) communication skills. Intervention effects were analyzed using linear mixed models.

Results: Participants (n = 152) were mostly female (89%) and psychologists (38%; physicians 26%; nurses 18%). F2F and EL participants reported high training satisfaction. Analyses did not reveal any significant differences on the primary outcome between groups, but indicate positive intervention effects over time regarding secondary outcomes including knowledge and self-efficacy in communication skills.

Conclusions: This is the first pilot-study evaluating a training for HCPs in oncology on parental cancer using a 3-armed RCT. The 3-h training program is a feasible approach and findings indicate to increase HCPs' knowledge and self-efficacy in caring for cancer patients with minor children. Further research is needed to verify preliminary findings of this pilot study. The study was pre-registered within the German Clinical Trial Register (DRKS-00015794).

Lene Marie Johannsen and Wiebke Frerichs contributed equally to this work.

KEYWORDS
cancer, communication, evaluation, family-centered care, medical education, oncology, parent, psycho-oncology, training

1 | INTRODUCTION

Parents with cancer are not only affected by disease-related burden, but also by concerns and fears regarding their children and their role as a parent.[1] As the parental cancer diagnosis impacts the whole family, minor and young adult children are confronted with changes in daily routines and reduced physical and emotional availability of their parents.[2] Between 7% and 88% of affected parents show substantially increased depression or anxiety levels.[3] Though most children cope well with the challenging situation, they are at risk to develop behavioral or emotional problems during the course of a parental cancer disease and its treatment.[4,5] Patient- and family-centered care is key to enhance high quality cancer care and must involve family and friends as a sixth dimension in patient-centered care.[6] However, children as relatives are often overlooked within the healthcare system and therefore may not receive the necessary support.[7,8] Affected parents wish for information and support in parental issues by their healthcare professionals (HCPs) (e.g., how to communicate with children),[9–11] but feel uncertain how to express their concerns and needs as a parent.[9] HCPs serve as gatekeepers by identifying cancer patients with minor children, their specific needs and worries and -if necessary- initiate supportive psychosocial care.[9] In Germany, national guidelines explicitly mention that all members of the oncological healthcare team are (to varying extents) responsible for the psychosocial care of patients, including for example, physicians or nurses.[12,13] Nevertheless, HCPs rarely address child- and family-specific themes proactively in daily routines.[8,10,14,15] Apart from time constraints and structural issues, lack of expertise and self-efficacy in their own skills when caring for cancer patients with minor children are reported barriers in supporting affected parents.[2,10,16–18] As competencies do not change with experience alone,[19] considerable effort is needed to increase HCP's knowledge, skills and self-efficacy regarding child- and family-related themes in cancer care. Despite the high need,[20,21] only few studies developed and evaluated specific interventions for HCPs on the subject of parental cancer.[14,20]

Hence, we developed an interprofessional 3-h educational training for HCPs in oncology to enhance their competencies in caring for cancer patients parenting minor children.[20] Training was either delivered as a face-to-face training (F2F) or a self-directed e-Learning (EL). This study aims at investigating:

(1) the **feasibility** of both training formats and the evaluation concept, and
(2) the preliminary **effectiveness** of the training regarding primary and secondary outcomes.

We hypothesized both intervention groups exhibiting significantly higher outcome improvements from baseline to post-training compared to waitlist-control group (CG).

2 | METHODS

The study was registered within the German Clinical Trial Register (DRKS-00015794) and approved by the Local Psychological Ethics Committee of the Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf, Germany (LPEK-001).

2.1 | Study design

This study was conducted as a randomized controlled pilot-trial (pilot-RCT) at the Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Germany.[20] Study groups (F2F, EL, CG) were compared regarding improvements over time in primary and secondary outcomes at three time points: before (t0, baseline before randomization), after (t1, post-training) and at 3-month follow-up (t2) (Figure 1).

2.2 | Participants and randomization

HCPs currently working in oncology, regardless of workplace setting (inpatient, outpatient), profession (e.g., physicians, nurses, psychologists) or work experience in oncology were recruited by e-mail or mail in North Germany from September 2019 to April 2021. During the Covid-19 pandemic, HCPs were recruited nationwide via email. Since we recruited via existing networks and lists and recipients were encouraged to forward study information to other HCPs, we cannot estimate the overall cohort number or number about decliners. All participants gave written informed consent before completing the baseline questionnaire. Physicians, psychologists, and nurses received continuing education credits for training participation. After the baseline assessment (t0), participants were stratified by their profession and randomly assigned to study groups. Post-training assessment (t1) was conducted 2–3 weeks after training participation (F2F), 6–8 weeks after sending EL access data, or 6 weeks after returning the baseline questionnaire (CG). Follow-up assessment (t2) was conducted 3 months after training participation (F2F) or 3 months after returning t1 (EL, CG). CG participants were offered to participate in a training of their choice (F2F or EL) after t1 assessment.

2.3 | Intervention

Development and detailed content of the training are described elsewhere.[22] The training comprised three modules (Figure 2), focusing on the disease's impact on the family, children's reaction to parental disease and the communication within and with families. For more information on training content, see Supporting Information S1.

The 3-h training program was delivered either as a F2F format with a maximum of 8 participants or as a self-administered EL program. Due to COVID-19 pandemic and related contact-restrictions in Germany starting in March 2020, original F2F was adapted to an interactive web-based F2F (≤8 participants). Both F2F training formats were conducted interprofessionally, applied various didactic methods (e.g., lectures, discussion rounds, audio-visual material and experience exchange) and were conducted by two facilitators. Two trainers have a psychological (LI, LMJ) and one trainer has a health science background (WF). EL participants received access using a code and could work stepwise through the training by buffering the training success. In the EL, various didactic methods were used, such as quiz rounds, matching, self-reflection exercises and audio-visual material (comparable with F2F format).

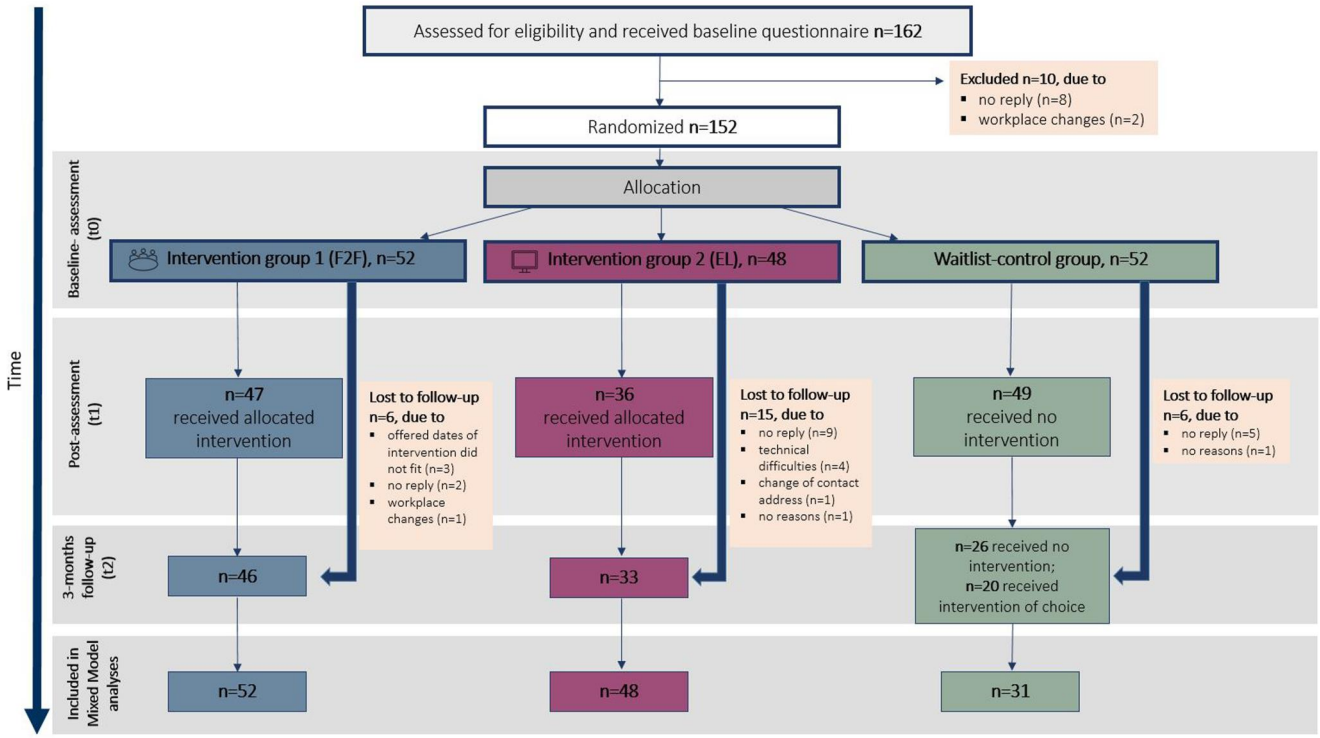

FIGURE 1 Study enrollment according to the Consolidated Standards of Reporting Trials (CONSORT) 2010 flow diagram.

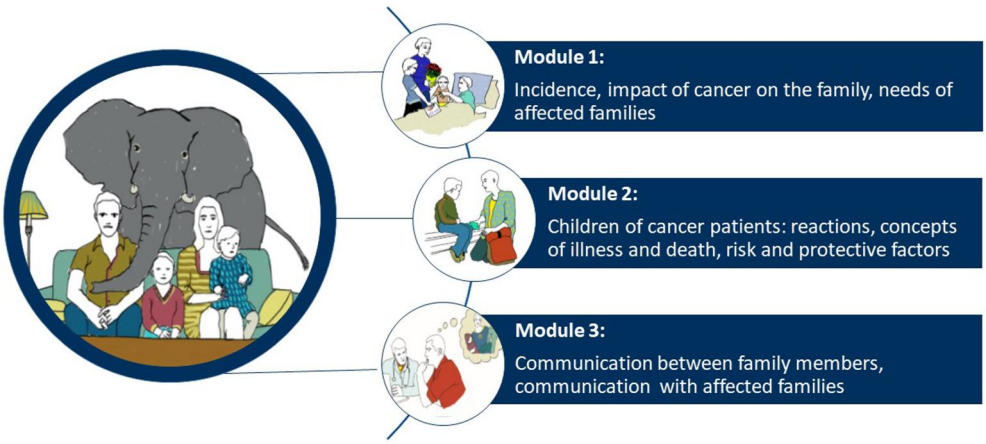

FIGURE 2 Content of the developed training program.

2.4 | Outcome measures

The training's pilot-evaluation was based on three levels of the Kirkpatrick's model of program evaluation: reaction (cf. Aim 1, feasibility and trainings satisfaction), learning and behavior (cf. Aim 2, preliminary effectiveness of the training).[23] Beyond feasibility and effectiveness, we assessed sociodemographic information, job-related fulfillment and burnout.

2.4.1 | Feasibility: Participants' training satisfaction

Feasibility and acceptability of the training were assessed using self-developed items. General items referring to both training formats were complemented by format-specific items and items on general format preference, rated on a 4-point Likert-scale (1: *I do not agree at all* to 4: *totally agree*).

2.4.2 | Preliminary effectiveness: Primary outcome

Primary outcome was the competency to approach child- and family-related themes in cancer patients. We developed a specific assessment tool, combining clinical case vignettes and situational judgment test methodology.[24] Each questionnaire included two clinical scenarios, reflecting cases of parents with cancer and measuring four domains: (1) *transfer of knowledge* into clinical practice, (2) *empathic behavior* toward affected parents, (3) integration of child- and family-related themes into clinical practice (*behavior*) and (4) *perceived relevance* of integration. Participants rated their *behavior* and its perceived *relevance* on a 4-point Likert-Scale. A pre-developed scoring guide was used to assess open responses in the domains of *knowledge transfer* and *empathy*. Answers were rated independently by two researchers (LJ, WF), and discussed in case of discrepancy. Across both scenarios, possible total score ranged from 0 to 14 for *knowledge transfer* and from 0 to 4 for *empathy*. Sum scores for *knowledge transfer* and *empathy* and mean scores for *behavior* and *relevance* were calculated across both scenarios of one measurement point.

2.4.3 | Preliminary effectiveness: Secondary outcomes

Knowledge

To assess specific knowledge on child- and family-related themes, we developed eight items based on training content (e.g., patient's barriers to use support offers). Two raters (LJ, WF) independently assessed participants' answers based on a pre-developed scoring guide (maximum score of 17.5 points).

Self-efficacy

Participant's self-efficacy was assessed using an adapted questionnaire (SE-12-G) with two subscales (confidence in [scale 1] and importance of communication skills [scale 2]). The original version (*Self-Efficacy of Communication Skills* scale, SE-12) was translated into German following the TRAPD translation protocol[25] and adapted for this study.[26] To assess self-efficacy in *child- and family-specific communication skills and related attitudes* with the same two subscales (confidence- and importance-scale), we constructed five additional items (SE-fam) based on a previous, adapted SE-12 version.[27] Items of the *confidence-scale* were rated on a 10-point rating scale ("*How certain are you…*"; 1: *very uncertain* to 10: *very certain*) and items of the perceived *importance-scale* on a 5-point-Likert-scale ("*How important is it…*"; 1: *not important at all to* 5: *very important*), with an additional check box "*not relevant*." The original SE-12 revealed acceptable test-retest reliability and high internal consistency and ceiling effects in 9 of 12 items.[26]

Communication behavior

HCPs' behavior regarding child- and family-related themes in their daily practice was assessed by 15 self-developed items (e.g., "*How often do you ask cancer patients/relatives about their concerns or worries as a parent?*") using a 4-point Likert scale (1: *never* to 4: *always*).

2.4.4 | Covariates

Professional fulfillment

To assess HCPs professional fulfillment and burnout, we translated the Professional Fulfillment Index (PFI)[28] into German applying the TRAPD translation protocol.[25] The 16-item questionnaire comprises three main scales (1) *professional fulfillment*, (2) *work exhaustion* and (3) *interpersonal disengagement* as well as an *overall burnout scale*. The *overall burnout scale* was used as a covariate within the main analysis. Items were rated on a 5-point Likert scale (0: *not at all* to 4: *completely true/extremely*). The original PFI revealed good internal consistency and test-retest reliability with an adequate sensitivity of all scales.[28]

2.5 | Sample size calculation

We used an approach for pilot studies to determine the sample size.[29] As a 10% probability for an unforeseen problem to occur and a 95% confidence interval (CI) to detect these problems was assumed, a necessary sample size of $n = 30$ participants in each study group was calculated. Considering a drop-out rate of 30%, $n = 108$ participants ($n = 36$ per group) were aimed to be included in the study. Drop-out was defined as not sending back the respective questionnaires despite three reminders.

2.6 | Statistical analyses

Descriptive statistics were used to analyze sample characteristics and participants' expectations and training motivation. Non-parametric tests were used to analyze participants' training

satisfaction including between-group comparisons (F2F vs. EL). ANOVA and chi-square tests were used to analyze differences between study groups at baseline (e.g., age, gender). Drop-out analyses were performed to analyze differences between completers and non-completers regarding sociodemographic and job-related baseline characteristics. We used linear mixed model analyses with repeated measures to compare outcome improvements between study groups over time. This method accounts for missing values conditional on the information available in the model.[30] Following a guideline on the adjustment for baseline covariates,[31] we calculated mixed models using change from baseline (CFB) values as outcome, study group, time, HCP group and the interaction term of "study group × time" as fixed main effects, and age, sex, overall burnout score and the outcomes' baseline values as covariates. To model interindividual differences, we included random intercept. We set the hierarchical model assuming a heterogeneous autoregressive covariance structure of residuals. Due to the small number of social workers and resulting unbalanced group sizes, we merged the groups of social workers and other professions for mixed model analyses into one group.

3 | RESULTS

3.1 | Eligibility and drop-out

162 participants gave their informed consent for participation. Of these, 152 returned the baseline assessment and were randomly assigned to F2F ($n = 52$), EL ($n = 48$) or CG ($n = 52$). Study groups did not differ significantly regarding participants' baseline sociodemographic variables. Drop-out analyses did not show any significant baseline differences between completers and non-completers. Across all study groups, 27 individuals dropped out between baseline and follow-up with a significant higher dropout in EL ($n = 15$) compared to F2F ($n = 6$) or CG ($n = 6$). Participants' reasons for dropout were for example, no reply despite three reminders ($n = 15$), technical problems with EL ($n = 4$) or no suitable date for F2F participation ($n = 3$).

3.2 | Sample characteristics

Participants were mainly psychologists (37.5%), followed by physicians (26.3%, mainly working in gynecology [53%] or in oncology and/or palliative care [22.5%]), nurses (18.4%), social workers (9.9%) and other health professions (7.9%, e.g., music therapists) (Table 1). Across all professional groups motivation and expectations for participation were to better address patient's needs ($n = 137$, 90%) to increase knowledge about the burden of affected parents ($n = 135$, 89%) and about reactions of children to the parental disease ($n = 133$, 88%) (cf. Supporting Information S2).

3.3 | Aim 1: Feasibility of the training program and the evaluation concept

3.3.1 | Training satisfaction

Overall, participants were highly satisfied with both training formats and there were no significant differences between the F2F and EL participants (cf. Supporting Information S3). Post-training, participants generally rated both formats as highly supportive, feasible and acceptable. For additional information on format-specific satisfaction and satisfaction at t1 and t2, see Supporting Information S4. Regarding the *feasibility of the evaluation concept*, high response rates of questionnaires and small numbers of missing values indicate the instruments being usable and feasible.

3.4 | Aim 2: Preliminary effectiveness of the training

Observed outcome values and results of mixed model analyses for primary and secondary outcomes are presented in Table 2. Primary outcome. Regarding the competency to approach child- and family-related themes, analyses indicated no significant differences over time between study groups in any of the four competency domains (*knowledge transfer*, *empathy*, *behavior*, *relevance*). Secondary outcomes. Analyzing improvements of *knowledge about child- and family-specific themes*, F2F showed significantly higher improvements than CG from t0 to t1 and greater improvements than EL when comparing t0 and t2. Results on *self-efficacy in communication skills* (SE-12-G) indicate F2F and EL being superior to CG (when comparing t0 and t1). Regarding *self-efficacy in child- and family-specific communication skills and related attitudes* (SE-fam), results on the confidence-scale also indicate F2F and EL being superior to CG (over all 3 measurements). Regarding results on the perceived importance-scale, F2F and EL showed greater improvements compared to CG from t0 to t1, comparing baseline with t2, effects only appeared in F2F (see Table 2 for further results).

Regarding HCPs' *communication behavior about child- and family-related themes in daily practice*, intervention groups significantly improved over time compared to CG in various items, for example, asked more frequently about children, children's age, patients' emotional burden, and talked more frequently about children's possible reactions or specialized support offers (cf. Supporting Information S5).

4 | DISCUSSION

We evaluated the effectiveness of a training for HCPs on parental cancer by comparing a F2F with an EL and a waitlist-control group (CG). Participants rated both training formats as highly satisfying and feasible. Furthermore, low drop-out rates and low numbers of

TABLE 1 Sample characteristics at baseline (t0, $n = 152$).

	Total ($n = 152$)	F2F ($n = 52$)	EL ($n = 48$)	CG ($n = 52$)
Age, M (SD) [range]	44.42 (11.6) [24–71]	45.64 (11.84) [24–71]	43.76 (10.51) [25–61]	46 (12.4) [25–63]
Sex, *n* (%)				
Female	134 (88.2)	42 (80.8)	44 (91.7)	48 (92.3)
Male	18 (11.8)	10 (19.2)	4 (8.3)	4 (7.7)
Professional group, *n* (%)				
Physician	40 (26.3)	12 (23.1)	13 (27.1)	15 (28.8)
Nurse	28 (18.4)	10 (19.2)	8 (16.7)	10 (19.2)
Psychologist	57 (37.5)	18 (34.6)	21 (43.8)	18 (34.6)
Social worker/other	27 (17.8)	12 (23.1)	6 (12.5)	9 (17.3)
Workplace setting[a], *n* (%)				
Outpatient	94 (61.8)	34 (65.4)	28 (58.3)	32 (61.5)
Inpatient	84 (55.3)	25 (48.1)	31 (64.6)	28 (53.8)
Self-employed/registered	25 (16.4)	10 (19.2)	6 (12.5)	9 (17.3)
Other	8 (5.3)	2 (3.8)	2 (4.2)	4 (7.7)
Professional experience with cancer patients, *n* (%)				
<1 year	13 (8.6)	2 (3.8)	4 (8.5)	7 (13.5)
1–5 years	46 (30.5)	18 (34.6)	12 (25.5)	16 (30.8)
6–10 years	33 (21.9)	10 (19.2)	14 (29.8)	9 (17.3)
>11 years	59 (39.1)	22 (42.3)	17 (36.2)	20 (38.5)
Amount of cancer patients per month, No. M (SD) [range], %	67.4 (33.0) [0.1–100], $n = 143$	67.3 (32.1) [4–100], $n = 49$	71.5 (32.1) [2–100], $n = 45$	63.9 (35) [4–100], $n = 49$
Amount of cancer patients parenting minor children, M (SD) [range] in %	21.4 (21.9) [0–100], $n = 123$	21.0 (23.3) [0–100], $n = 42$	21.9 (22.3) [0.1–100], $n = 40$	21.2 (30.4) [0–95], $n = 41$

Abbreviations: CG, waitlist-control group; EL, e-learning; F2F, face-to-face training; M, mean; SD, standard deviation.

[a]Multiple answers possible.

missing values indicate high acceptability of both the trainings and the applied evaluation measures. While the training did not significantly increase participants' *competencies to address child- and family-related themes* over time compared to CG, analyses indicate significant positive intervention effects over time for secondary outcomes, mainly for *self-efficacy in communication skills* (including *child-and family-specific communication skills*) and *communication behavior about child- and family-related themes in daily practice*. Our results are in line with two previous studies indicating improvements in communication skills, knowledge and self-efficacy after participation in a training for HCPs on parental cancer.[14,20] However, results should be interpreted with caution due to self-reported measures, as findings indicate a positive shift to a more proactive and patient-oriented behavior after training.

Since analyses revealed positive intervention effects in knowledge, self-efficacy and communication behavior, training might contribute to reduce barriers of HCPs (e.g., lack of knowledge and self-efficacy) and promote a proactive and patient-oriented communication with affected parents.[18] Enhancing HCPs in their knowledge and self-efficacy around child- and family-related themes may support early identification of specific needs and facilitates referral to family-support offers for affected families.[9,32,33]

Our results indicate comparable preliminary effectiveness of both training formats as overall F2F participants do not show higher improvements compared to EL participants. However, higher drop-out rates and participants' feedback indicate higher preference for the F2F format (cf. Supporting Information S4d). At the same time, HCPs experience various barriers in daily clinical routine to participate in a F2F intervention, for example, time constraints.[34] EL might be an adequate alternative to F2F, as it is a more flexible approach.[34] As evidence for EL interventions on patient-reported outcomes is low,[34] the pros and cons of EL interventions should be considered carefully when designing trainings for HCPs. Still, location independent training formats, including self-directed EL and web-based live-training, play an important role in providing education, especially during the COVID-19 pandemic.

TABLE 2 Observed primary and secondary outcome results of longitudinal mixed model analyses.

	Descriptive data per study group				Pairwise group comparisons						
					F2F versus CG		EL versus CG		F2F versus EL		
	F2F[a]	EL[a]	CG[a]	CFB	M_{diff} [CI], *p*						Global effect *interaction*[b] *group×time*
	M (SD)										
Primary outcome *(competency to address child- and family related themes)*											
Knowledge transfer											0.437
T0	6.15 (2.00)	7.10 (1.88)	6.31 (1.91)								
T1	8.11 (1.45)	8.45 (1.42)	8.73 (1.35)	T1-T0	−0.065 [−1.195; 1.066]	0.91	−0.007 [−1.222; 1.209]	0.991	−0.058 [−1.07; 0.954]	0.91	
T2	7.23 (1.67)	6.80 (2.25)	7.08 (1.80)	T2-T0	0.153 [−0.967; 1.274]	0.787	−0.517 [−1.63; 0.595]	0.358	0.671 [−0.302; 1.644]	0.175	
Empathy											0.138
T0	3.3 (0.83)	3.57 (0.50)	3.78 (0.89)								
T1	3.45 (0.56)	3.59 (0.34)	3.54 (0.46)	T1-T0	−0.201 [−0.58; 0.178]	0.296	−0.066 [−0.469; 0.337]	0.745	−0.134 [−0.444; 0.175]	0.392	
T2	3.26 (0.58)	3.05 (0.58)	3.06 (0.50)	T2-T0	0.228 [−0.133; 0.588]	0.214	0.036 [−0.328; 0.401]	0.844	0.191 [−0.121; 0.504]	0.228	
Behavior											0.451
T0	3.60 (0.35)	3.65 (0.39)	3.65 (0.29)								
T1	3.63 (0.34)	3.75 (0.32)	3.67 (0.33)	T1-T0	−0.02 [−0.185; 0.147]	0.814	0.086 [−0.086; 0.258]	0.322	−0.106 [−0.241; 0.029]	0.122	
T2	3.73 (0.35)	3.72 (0.32)	3.58 (0.37)	T2-T0	0.095 [−0.067; 0.256]	0.248	0.156 [−0.004; 0.316]	0.056	−0.061 [−0.197; 0.075]	0.375	
Perceived relevance											0.846
T0	3.71 (0.32)	3.8 (0.24)	3.71 (0.24)								
T1	3.72 (0.32)	3.79 (0.30)	3.73 (0.28)	T1-T0	0.004 [−0.16; 0.168]	0.962	0.021 [−0.147; 0.189]	0.803	−0.017 [−0.152; 0.117]	0.8	
T2	3.78 (0.35)	3.82 (0.29)	3.68 (0.39)	T2-T0	0.013 [−0.147; 0.172]	0.876	0.065 [−0.093; 0.223]	0.415	−0.053 [−0.191; 0.085]	0.452	
Secondary outcomes											
Knowledge *(about child- and family-specific themes)*											0.06
T0	9.28 (2.65)	10.99 (1.83)	9.75 (2.67)								
T1	11.01 (2.84)	11.23 (3.24)	9.46 (2.53)	T1-T0	2.037 [0.601; 3.473]	**0.006***	1.194 [−0.267; 2.656]	0.108	0.842 [−0.407; 2.091]	0.184	
T2	11.16 (3.04)	10.82 (2.32)	10.17 (3.00)	T2-T0	1.164 [−0.254; 2.582]	0.107	−0.433 [−1.846; 0.979]	0.544	1.598 [0.356; 2.84]	**0.012***	
Self-efficacy in communication skills											
SE-12-confidence											487
T0	8.10 (0.96)	8.00 (0.86)	8.16 (1.02)								
T1	8.42 (0.85)	8.28 (0.83)	8.10 (1.03)	T1-T0	0.414 [0.047; 0.78]	**0.027***	0.432 [0.052; 0.813]	**0.026***	−0.019 [−0.323; 0.285]	0.903	
T2	8.34 (0.82)	8.22 (0.87)	8.28 (0.92)	T2-T0	0.132 [−0.223; 0.486]	0.463	0.199 [−0.157; 0.555]	0.271	−0.067 [−0.365; 0.23]	0.656	
SE-12-importance											0.493
T0	4.58 (0.34)	4.74 (0.32)	4.67 (0.29)								
T1	4.65 (0.35)	4.72 (0.33)	4.57 (0.39)	T1-T0	0.229 [0.059; 0.4]	**0.009***	0.163 [−0.012; 0.337]	0.067	0.067 [−0.073; 0.207]	0.348	
T2	4.58 (0.38)	4.66 (0.42)	4.60 (0.34)	T2-T0	0.113 [−0.054; 0.281]	0.183	0.07 [−0.095; 0.236]	0.401	0.043 [−0.102; 0.188]	0.56	

(Continues)

TABLE 2 (Continued)

	Descriptive data per study group				Pairwise group comparisons						
	F2F[a]	EL[a]	CG[a]		F2F versus CG		EL versus CG		F2F versus EL		Global effect *interaction*[b] *group*×*time*
	M (SD)			CFB	M_{diff} [CI], *p*						
Self-efficacy in child- and family-specific communication skills and related attitudes											
SE-fam-confidence											0.92
T0	7.05 (1.79)	6.96 (1.21)	6.55 (1.65)								
T1	8.02 (1.13)	7.81 (0.88)	7.04 (1.56)	T1-T0	0.868 [0.291; 1.445]	**0.004***	0.683 [0.091; 1.275]	**0.024***	0.185 [−0.275; 0.645]	0.428	
T2	8.06 (0.91)	7.8 (1.05)	7.25 (1.20)	T2-T0	0.754 [0.213; 1.294]	**0.007***	0.549 [0.006; 1.092]	**0.048***	0.205 [−0.256; 0.665]	0.38	
SE-fam-importance											0.844
T0	4.38 (0.52)	4.65 (0.47)	4.51 (0.52)								
T1	4.60 (0.41)	4.70 (0.44)	4.52 (0.43)	T1-T0	0.308 [0.106; 0.51]	**0.003***	0.238 [0.034; 0.442]	**0.023***	0.07 [−0.093; 0.233]	0.396	
T2	4.61 (0.38)	4.64 (0.50)	4.37 (0.71)	T2-T0	0.29 [0.098; 0.483]	**0.004***	0.186 [−0.006; 0.377]	0.057	0.105 [−0.062; 0.271]	0.215	

Note: Bold font indicates statistical significance.

[a]$n = 52$ (F2F), $n = 48$ (EL), $n = 31$ (CG); sample sizes slightly differ, as single items were not answered by all respondents.

[b]Global effect as interaction between *study group* (F2F, EL, CG) and *time* (T0, T1, T2). Results are expressed as mean (M), standard deviation (SD), mean difference (M_{diff}), confidence interval (CI), change from baseline (CFB), *p*-value (*p*).

*$p < 0.05$; In the mixed model analyses following variables were set as fixed main effects: *study group*, *time*, *HCP group* and the interaction term of *study group* × *time*. *Age*, *sex*, *overall burnout score* and the *outcome's baseline values* were included as covariates.

4.1 | Study limitations

Results must be interpreted with caution, since this study was conducted as a pilot-RCT and sample size was not calculated based on expected effects. Recruitment through e-mail distribution lists and a snowball effect does not allow to provide information on decliners and overall cohort numbers. Moreover, volunteer bias might have influenced the data as participants might have been highly motivated and interested in the topic. These aspects may explain ceiling effects in several outcome measures. Whereas the low number of missings and high response rate indicate feasibility of the evaluation concept and instruments, these were mainly based on self-report, self-developed and, so far, not psychometrically tested. Clinical vignettes as an external assessment of hypothetical, context-specific situation have been chosen due to vignettes' rise in research[35] and for organizational reasons. Future studies might additionally use external rating (e.g., simulated patient assessments) to capture observable communication changes or the perspective of patients as an outcome parameter for the effectiveness of a training for HCPs and to investigate how patients and children perceive interactions with HCPs after attending a training. Additionally, we used linear mixed models including the outcomes' baseline values as a covariate, an approach considered to be more precise, but variance may be limited and effects may be underestimated.[31]

4.2 | Clinical implications

Identifying cancer patients with minor children and assessing their specific supportive needs is imperative for HCPs to provide adequate cancer care and, in a best practice scenario, refer families in need to family- or child-centered support programs or services.[32,36–39] Our findings indicate that a 3-h-training on parental cancer can increase HCPs' knowledge and self-efficacy. It thus has the potential to improve the situation of affected families by enhancing the HCPs' self-efficacy to address the needs of affected parents (e.g., how to communicate with children about cancer). The training might be complemented by routine screening for patient and family needs as well as the implementation of family- and child-centered support programs or services.[32,36–39] As HCPs have different professional backgrounds and experiences, their needs regarding intensity and length of the training might differ. Therefore, an adaptation specifically tailored to the different HCP groups might be advantageous to deepen specific knowledge and skills within the different professions.

5 | CONCLUSIONS

Findings of our pilot evaluation of a training for HCPs on parental cancer indicate no improvements in the *competency to approach child- and family-related themes* after training, but improvements on *knowledge, self-efficacy, and family-oriented communication* of HCPs. To ensure long-term improvements in HCPs' knowledge, self-efficacy, and family-oriented communication, "refresher courses" after basic training might be a suitable approach. Participants were highly satisfied with both training formats. Although EL seems to be an adequate alternative to F2F, enabling time- and location-independent education, participants mainly preferred F2F. Overall, findings indicate the training being a promising and feasible approach to enhance HCPs' knowledge and self-efficacy in caring for parents with cancer. Further research is needed to verify the preliminary findings of this pilot-study.

AUTHOR CONTRIBUTIONS

Lene Marie Johannsen: Conceptualization; data curation; formal analysis; investigation; methodology; project administration; resources; validation; visualization; writing – original draft. **Wiebke Frerichs**: Conceptualization; data curation; formal analysis; investigation; methodology; project administration; resources; validation; visualization; writing – original draft. **Rebecca Philipp**: Formal analysis; methodology; validation; writing – review and editing. **Laura Inhestern**: Conceptualization; funding acquisition; investigation; methodology; project administration; resources; supervision; writing – review and editing. **Corinna Bergelt**: Conceptualization; funding acquisition; methodology; project administration; resources; supervision; writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have nothing to disclose.

DATA AVAILABILITY STATEMENT

De-identified data that support the findings of this study are available on reasonable request. Investigators who propose to use the data have to provide a methodologically sound proposal directed to the corresponding author. Signing a data use/sharing agreement will be necessary, and data security regulations both in Germany and in the country of the investigator who proposes to use the data must be complied with. Preparing the data set for use by other investigators requires substantial work and is thus linked to available or provided resources.

ETHICS STATEMENT

This study was approved by the Local Psychological Ethics Committee of the Center for Psychosocial Medicine at the University

Medical Center Hamburg-Eppendorf, Germany (reference number LPEK-001).

COMPETING INTERESTS

The authors declare that they have no competing interests.

CONSENT TO PARTICIPATE

We obtained written informed consent from all patients participating in the study. Study participation was voluntary.

STATISTICAL METHODS

Used statistical methods included descriptive statistics, non-parametric tests, ANOVA and chi-square tests, binomial logistic regression, Mann-Whitney-U test, linear mixed model analyses with repeated measures (including CFB and random intercept).

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REFERENCES

1. Kuswanto CN, Stafford L, Sharp J, Schofield P. Psychological distress, role, and identity changes in mothers following a diagnosis of cancer: a systematic review. *Psycho Oncol*. 2018;27(12):2700-2708. https://doi.org/10.1002/pon.4904
2. Konings S, McDonald FEJ, Patterson P. Supporting parents impacted by cancer: development of an informational booklet for parents with cancer who have adolescent and young adult children. *Psycho Oncol*. 2020;29(12):2101-2104. https://doi.org/10.1002/pon.5475
3. Johannsen L, Brandt M, Frerichs W, Inhestern L, Bergelt C. The impact of cancer on the mental health of patients parenting minor children: a systematic review of quantitative evidence. *Psycho Oncol*. 2022;31(6):869-878. https://doi.org/10.1002/pon.5912
4. Inhestern L, Johannsen LM, Bergelt C. Families affected by parental cancer: quality of life, impact on children and psychosocial care needs. *Front Psychiatry*. 2021;12. https://doi.org/10.3389/fpsyt.2021.765327
5. Morris JN, Martini A, Preen D. The well-being of children impacted by a parent with cancer: an integrative review. *Support Care Cancer*. 2016;24:3235-3251. https://doi.org/10.1007/s00520-016-3214-2
6. Richardson WC, Berwick DM, Bisgard JC, et al. *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academy Press; 2001.
7. Alexander E, O'Connor M, Halkett GKB. The perceived effect of parental cancer on children still living at home: according to oncology health professionals. *Eur J Cancer Care*. 2020;29(6):e13321. https://doi.org/10.1111/ecc.13321
8. Dencker A, Murray SA, Mason B, Rix BA, Bøge P, Tjørnhøj-Thomsen T. Disrupted biographies and balancing identities: a qualitative study of cancer patients' communication with healthcare professionals about dependent children. *Eur J Cancer Care*. 2019;28(2):e12991. https://doi.org/10.1111/ecc.12991
9. Fearnley R, Boland JW. Communication and support from healthcare professionals to families, with dependent children, following the diagnosis of parental life-limiting illness: a systematic review. *Palliat Med*. 2017;31(3):212-222. https://doi.org/10.1177/0269216316655736
10. Dencker A, Rix BA, Boge P, Tjornhoj-Thomsen T. A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children. *Psycho Oncol*. 2017;26(12):2162-2167. https://doi.org/10.1002/pon.4440
11. Dalton L, Rapa E, Ziebland S, et al. Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent. *Lancet*. 2019;393(10176):1164-1176. https://doi.org/10.1016/s0140-6736(18)33202-1
12. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF). S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.4. AWMF Registernummer: 032-045OL. 2021. Accessed August 08, 2023. http://www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom/
13. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF). Psychoonkologische Diagnostik, Beratung und Behandlung von erwachsenen Krebspatient*innen, Langversion 2.0. AWMF-Registernummer: 032-051OL. 2023. Accessed August 08, 2023. https://www.leitlinienprogramm-onkologie.de/leitlinien/psychoonkologie/
14. Turner J, Clavarino A, Butow P, et al. Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention. *Eur J Cancer*. 2009;45(10):1798-1806. https://doi.org/10.1016/j.ejca.2009.02.023
15. Schouten B, Bergs J, Vankrunkelsven P, Hellings J. Healthcare professionals' perspectives on the prevalence, barriers and management of psychosocial issues in cancer care: a mixed methods study. *Eur J Cancer Care*. 2019;28(1):e12936. https://doi.org/10.1111/ecc.12936
16. Ernst JC, Beierlein V, Romer G, Möller B, Koch U, Bergelt C. Use and need for psychosocial support in cancer patients. *Cancer*. 2013;119(12):2333-2341. https://doi.org/10.1002/cncr.28021
17. Fagerlind H, Kettis Å, Glimelius B, Ring L. Barriers against psychosocial communication: oncologists' perceptions. *J Clin Oncol*. 2013;31(30):3815-3822. https://doi.org/10.1200/jco.2012.45.1609
18. Heynemann S, Philip J, McLachlan S-A. An exploration of the perceptions, experience and practice of cancer clinicians in caring for patients with cancer who are also parents of dependent-age children. *Support Care Cancer*. 2021;29(7):3895-3902. https://doi.org/10.1007/s00520-020-05969-x
19. Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev*. 2013;2013:Cd003751. https://doi.org/10.1002/14651858.cd003751.pub3
20. Semple C, McCaughan E, Smith R. How education on managing parental cancer can improve family communication. *Cancer Nurs Pract*. 2017;16(5):34-40. https://doi.org/10.7748/cnp.2017.e1406
21. Semple CJ, McCaughan E. Developing and testing a theory-driven e-learning intervention to equip healthcare professionals to communicate with parents impacted by parental cancer. *Eur J Oncol Nurs*. 2019;41:126-134. https://doi.org/10.1016/j.ejon.2019.05.006
22. Inhestern L, Frerichs W, Johannsen LM, Bergelt C. Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot study. *BMJ Open*. 2019;9(10):e032778. https://doi.org/10.1136/bmjopen-2019-032778
23. Kirkpatrick D, Kirkpatrick J. *Evaluating Training Programs: The Four Levels*. Berrett-Koehler Publishers; 2006.
24. Johannsen LM, Frerichs W, Inhestern L, Bergelt C. Assessing competencies of healthcare professionals caring for parents with cancer: the development of an innovative assessment tool. *Psycho Oncol*. 2020;29(10):1670-1677. https://doi.org/10.1002/pon.5507

25. Mohler P, Dorer B, De Jong J, Hu M. *Translation. Guidelines for Best Practice in Cross-Cultural Surveys*. Survey Research Center. Institute for Social Research. University of Michigan; 2016.
26. Axboe MK, Christensen KS, Kofoed PE, Ammentorp J. Development and validation of a self-efficacy questionnaire (SE-12) measuring the clinical communication skills of health care professionals. *BMC Med Educ*. 2016;16(1):272. https://doi.org/10.1186/s12909-016-0798-7
27. Hvidt EA, Ammentorp J, Søndergaard J, Timmermann C, Hansen DG, Hvidt NC. Developing and evaluating a course programme to enhance existential communication with cancer patients in general practice. *Scand J Prim Health Care*. 2018;36(2):142-151. https://doi.org/10.1080/02813432.2018.1459235
28. Trockel M, Bohman B, Lesure E, et al. A brief instrument to assess both burnout and professional fulfillment in physicians: reliability and validity, including correlation with self-reported medical errors, in a sample of resident and practicing physicians. *Acad Psychiatry*. 2018;42:1-24. https://doi.org/10.1007/s40596-017-0849-3
29. Viechtbauer W, Smits L, Kotz D, et al. A simple formula for the calculation of sample size in pilot studies. *J Clin Epidemiol*. 2015;68(11):1375-1379. https://doi.org/10.1016/j.jclinepi.2015.04.014
30. Chakraborty H, Gu H. *A Mixed Model Approach for Intent-To-Treat Analysis in Longitudinal Clinical Trials with Missing Values*. RTI Press; 2009.
31. Committee for Medicinal Products for Human Use (CHMP) guideline on adjustment for baseline covariates in clinical trials. 2015. Available online: Adjustment for baseline covariates in clinical trials - Scientific guideline | European Medicines Agency (europa.eu). Accessed January 13, 2023. https://www.ema.europa.eu/en/adjustment-baseline-covariates-clinical-trials-scientific-guideline
32. Inhestern L, Haller AC, Wlodarczyk O, Bergelt C. Psychosocial interventions for families with parental cancer and barriers and facilitators to implementation and use - a systematic review. *PLoS One*. 2016;11(6):e0156967. https://doi.org/10.1371/journal.pone.0156967
33. Justin P, Dorard G, Baudry V, Untas A. Oncology healthcare professionals' knowledge, attitudes, and practices regarding young carers. *Patient Educ Couns*. 2022;105(7):2524-2530. https://doi.org/10.1016/j.pec.2022.01.014
34. Berg MN, Ngune I, Schofield P, et al. Effectiveness of online communication skills training for cancer and palliative care health professionals: a systematic review. *Psycho Oncol*. 2021;30(9):1405-1419. https://doi.org/10.1002/pon.5702
35. Riley AH, Critchlow E, Birkenstock L, et al. Vignettes as research tools in global health communication: a systematic review of the literature from 2000 to 2020. *J Commun Healthc*. 2021;14(4):283-292. https://doi.org/10.1080/17538068.2021.1945766
36. Taylor-Brown J, Acheson A, Farber JM. Kids can cope: a group intervention for children whose parents have cancer. *J Psychosoc Oncol*. 1993;11(1):41-53. https://doi.org/10.1300/j077v11n01_03
37. Alexander E, O'Connor M, Rees C, Halkett G. A systematic review of the current interventions available to support children living with parental cancer. *Patient Educ Couns*. 2019;102(10):1812-1821. https://doi.org/10.1016/j.pec.2019.05.001
38. Skrabal Ross X, McDonald FEJ, Konings S, et al. Cancer patients as parents: implementation of a cross sector service for families with adolescent and young adult children. *BMC Health Serv Res*. 2023;23(1):1-13. https://doi.org/10.1186/s12913-023-09413-8
39. Geertz W, Frerichs W, Inhestern L, Bergelt C. Supportive and psychosocial peer-group interventions for children and adolescents of parents with cancer: a systematic review. *Patient Educ Counsel*. 2023;114:107844. https://doi.org/10.1016/j.pec.2023.107844

SUPPORTING INFORMATION

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Providing care to cancer patients parenting minor children: A qualitative study on healthcare professionals' communication practice

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ABSTRACT

Aim: To explore healthcare professionals' (HCPs) experiences when communicating about child- and family-related aspects in cancer care and their attitudes about the importance of including these aspects in cancer care.
Methods: We conduced semi-structured interviews with HCPs working in oncology. Interviews were audio-recorded, transcribed verbatim and analyzed using Kuckartz's method for qualitative content analysis.
Results: N = 20 HCPs working in oncology, either inpatient or outpatient setting in the area of Hamburg, Germany participated. N = 7 were nurses, n = 6 psychologists, n = 5 physicians and n = 2 social workers. Results showed that HCPs' communication about child- and family-related aspects for cancer patients parenting minor children varies widely, influenced by factors such as diagnosis, structural challenges, individual characteristics, or profession. Additionally, their attitudes about how relevant it is to integrate child- and family-related aspects in routine cancer care varies from low relevance (i.e. lower priority, beyond professional role) to high relevance (i.e. palliative cases, children have a right to know).
Conclusion: HCPs' communication practice and views on the importance of addressing child- and family-related aspects in cancer care vary widely and are shaped by various influences.
Practice implication: Results emphasize the need for training and resources to enhance HCPs communication competencies to provide family-oriented care proactively.

1. Background

Worldwide, up to 25 % of cancer patients are also parents of children, adolescents or young adults [1]. Cancer disrupts normal family life, routines, and roles [2]. When parents are diagnosed with cancer, they experience not only disease-related burden, but also concerns and needs related to their children and family, as managing the illness while fulfilling caregiving responsibilities is both physically and mentally stressful [3–5]. A recent systematic review indicated 7 %-83 % of parents having cancer present depression scores indicating a probable depression and 19 %-88 % of parents present anxiety scores indicating an anxiety disorder [6]. Parents often feel uncertain about how to communicate their cancer diagnosis to their children, due to a lack of confidence or emotional distress [7,8]. Providing age-appropriate information and open communication about parental cancer can decrease the risk of developing negative psychological and physical consequences in affected children [3,9] and can decrease parents' disease-related burden [10].

Parents with cancer often wish to receive support and advice from their healthcare professionals (HCPs) regarding child- and family specific aspects [11–13], but they rarely bring up these needs proactively [14,15]. At the same time, HCPs seldom address these aspects in routine cancer care [16–18]. A recent qualitative study found that only few parents reported HCPs addressing parental themes proactively and routinely in cancer care, and that these parents felt safe and recognized as parents [15]. Within this study, most parents reported that they were not routinely asked if they had minor children, or that parental themes only came up coincidentally. Parental themes appeared to be more likely to be discussed when the patient proactively asked for advice or help, if children were 'visible' (e.g., through photos in the hospital room, or when children were visiting) or when the parental burden was obvious [15].

From the HCPs' perspective, various barriers have been reported on why it is challenging to communicate about child- and family-related aspects when a patient is seriously ill or even dying. Studies report that HCPs feel incapable to provide care to (cancer) patients parenting

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minor children, e.g., due to lack of specific competencies, knowledge or confidence or due to structural barriers including time pressure [17, 19–22].

To ensure high-quality (cancer) care, it is essential to equip HCPs with the necessary competencies and knowledge regarding child- and family-related aspects [23,24]. As early-onset cancers rise [25], it is crucial for HCPs to routinely address child- and family-related aspects in cancer care. HCPs play a significant gatekeeper role in identifying patients with minor children, ensuring these parents receive vital information, resources, and referrals to specialized support services [16,19, 20,26]. While communication around cancer is well studied [27,28], a gap exists in understanding how HCPs navigate conversations with cancer patients who are also parents of minor children. Limited research has been conducted on how HCPs in oncology integrate the complexities of parenthood into their communication practices [17,20], and - to our knowledge - none have been conducted in Germany. This is a critical gap, given the importance of understanding the experiences and needs of HCPs within a particular setting and healthcare system to develop and implement specific interventions [29,30]. Therefore, this study aimed to address this gap through a qualitative investigation exploring:

a) HCPs' experiences when communicating about child- and family-related aspects in cancer care, and
b) their attitudes towards these aspects in cancer care.

2. Methods

2.1. Study design

A qualitative study was conducted analyzing data from semi-structured interviews with HCPs working in oncology using conventional content analysis [31]. The study follows the Standards for Reporting Qualitative Research guideline [32], which can be found in Appendix 1. This study was conducted as part of a larger research project, entailing the development and pilot-evaluation of a communication training for HCPs working in oncology [33,34], which was registered in the German Register of Clinical Studies (DRKS-00015794).

2.2. Study setting and recruitment

The study was conducted at the University Medical Center Hamburg-Eppendorf, an academic medical center in Northern Germany. Participants were identified through established professional networks and snowball recruitment in the greater Hamburg area. Purposive, convenience and consecutive sampling was used to recruit HCPs from in- and outpatient clinics. Participants were eligible if they currently work with cancer patients in an outpatient or inpatient setting and belong to one of the professional groups: physicians, nurses, psychologists (including psycho-oncologists), and social workers. Two authors (LI, WF) invited potential participants to take part in an interview by email, post or telephone. Interested individuals replied by phone or email confirming interest, and to arrange a date and time for the interview. Written informed consent was obtained prior to the interview from all participants.

2.3. Data collection

Semi-structured interviews were conducted between October 2018 and January 2019, either face-to-face or by telephone, based on participants' preference. A semi-structured interview guide was developed (see Appendix 2) by LI and WF based on evidence on current (international) literature on communication between HCPs and parents with cancer, the aims and objective of the study as well as the research team's experience in patient care and research on parental cancer. The interview guide was pilot tested during the first interview, and no subsequent modifications were made thereafter. The following themes were covered: a) HCP's current practice and experiences in cancer care dealing with child- and family-related aspects; b) attitude about the relevance of these aspects in cancer care; c) perceived needs of affected families; d) needs of HCPs to implement these aspects in cancer care; e) HCPs needs regarding specific communication skill training (CST). Additionally, within the interviews all participants were asked short questions regarding their demographic and occupational data. The interviews were conducted by LI (n = 17) and WF (n = 3). LI is a psychologist and licensed psychotherapist. WF is a health scientist focusing on psycho-oncology and patient-centered care. Both are experienced in conducting qualitative research.

2.4. Data analysis

All interviews were audio-recorded and transcribed verbatim using the f4transkript software [35], following the transcription rules of Dresing & Pehl [36] including anonymization of personal data. The transcripts were analyzed using qualitative content analysis, a systematic procedure that serves to reduce the data material while extracting essential content [37].

We performed data analysis as follows, using an iterative process, with repeated cycles of coding, review, and refinement: 1) Development of category system based on deductive categories from the research questions and interview guideline (WF, VM); 2) coding of 20 % (n = 4) transcripts (VM) developing gradually inductive categories, discussion with WF and mutual refinement; 3) independent coding of additional 20 % of transcripts followed by discussion and refinement (WF, VM); 4) continuous coding of remaining interview data (VM) with iterative review, discussions, and refinements with WF, until final coding system was applied to all data (VM); 5) comprehensive quality control by WF of all codings with discussions and iterative refinements among WF and LJ. The data was analyzed using MAXQDA software (Version 2020, VERBI GmbH, Berlin, Germany).

2.5. Ethical considerations

The study was carried out according to the latest version of the Helsinki Declaration of the World Medical Association. Ethics approval was obtained from the Local Psychological Ethics Committee of the Center for Psychosocial Medicine, Medical Center Hamburg-Eppendorf (LPEK-001). Each participant received both verbal and written information, had the chance to ask additional questions, and provided informed consent.

3. Results

3.1. Sample characteristics

We conducted n = 20 interviews with HCPs. Sample characteristics are presented in Table 1. Interviews lasted 15 −39 min (mean=26.3).

3.2. Results of the qualitative analysis

Based on the objectives of this study, two main categories were identified: (1) HCPs' experiences in communicating about child- and family-related aspects with cancer patients; and (2) their attitudes about the relevance of communicating these aspects in cancer care. Additional sub-categories were identified within these main categories. Representative quotes for the main and subcategories are presented in Table 2.

3.2.1. Experiences of HCPs in addressing child- and family-related aspects in cancer care

3.2.1.1. Identifying cancer patients parenting minor children. When exploring whether and when HCPs assess parental status of their

Table 1
Participants' characteristics (n=20).

Participants' characteristics (n = 20)	
Age, (in years), M (SD) [range]	41.7 (9.9) [24–62]
Sex, n (%)	
female	17 (85 %)
male	3 (15 %)
Professional group, n (%)	
Nurse	7 (35 %)
Psychologist (incl. Psycho-oncologist)	6 (30 %)
Medical physician	5 (25 %)
Social Worker	2 (10 %)
Amount of HCPs working within gynecology setting, n (%)	9 (45 %)
Professional experience in oncology, (in years) M (SD) [range]	10.7 (7.2) [1–23]
Estimated amount of cancer patients in daily practice, (in %) M (SD) [range]	84.0 % (16.3) [50–100]
Amount of cancer patients between 25 and 55 years, (in %) M (SD) [range]	43.7 % (43.6) [20–80]
Having access to/cooperation with specific child-centered counselling service (e.g., COSIP[1]), n (%)	12 (60 %)
Having children him-/herself, n (%)	11 (55 %)

Abbreviations: n: study population; M: mean; SD: standard deviation.
Note: [1]Child-centred counselling (COSIP [38]) for cancer patients with children ≤ 21 years and their family members, at the time of the interviews offered at University Medical Center Hamburg-Eppendorf, Germany.

patients, they reported diverse communication practice in cancer care, also depending on the setting. Some HCPs reported to consistently identify cancer patients as parents of minor children in a structured manner (e.g., through psycho-oncology screening or medical history taking), followed by assessing whether these patients might benefit from specialized support services for parents with cancer.

Others reported that they only inquire about minor children if the patients appear younger or mention their children themselves, assuming patients around 55 or older do not have minor children.

3.2.1.2. Identifying psychosocial aspects and supportive needs in cancer care. When exploring if and how HCPs identify relevant psychosocial aspects in cancer care, HCPs specifically from the (psycho-)social professions reported that identifying these aspects is an integral part of their communication techniques and, therefore, always occurs within the patient-provider interaction. They experienced that through asking open-ended questions about patients' concerns, child- and family-related aspects naturally arise if they are of concern to the patients, opening the door to refer to specialized support services. Some HCPs from the nursing or physician professionals reported that they would also inquire about these aspects when talking to their patients. However, one nurse reported her experience that when she asked her nursing colleagues about their reluctance to discuss these aspects with patients, some admitted they were uncertain about how to initiate these conversation.

During routine patient-provider interactions, few HCPs, who regularly identify social resources and support during cancer care experienced patients reacting with surprise to these questions, as they had not been asked such aspects before.

3.2.1.3. Advice on how to communicate with children. Some HCPs also reported that during cancer care, they assess whether the children are aware of the parent's illness, provide advice on the importance of open communication with children, and discuss how such communication can take place. One nurse shared her experience of openly advising a cancer parents to be honest with their child about the reason for the hospital visit, despite feeling uncertain about how to give such advice. Some HCPs reported, that they experience these conversations about open communication a good opportunity to offer supportive materials, such as children's books or apps.

3.2.1.4. Referral to specialized support services. HCPs frequently

Table 2
Representative quotes for sub-categories.

Representative quotes for sub-categories	
Experiences of HCPs in addressing child- and family-related aspects in cancer care	
Identifying cancer patients parenting minor children	*"Yes "I work in a consultative manner […], and I also work in outpatient psychotherapy, and the two fields differ significantly in terms of structure. In the outpatient context: Yes, of course [I ask the patient if he or she has under aged children], in the inpatient context, as soon as a patient of the appropriate age is willing to engage in a conversation, the discussion usually inevitably turns to relatives and children."* [Psychologist, #6]
	"No, because it never comes up. [At admission or something similar], it's not asked. Well, not by me. It usually comes up in conversation that the children are mentioned. […] But the proportion is very low." [Nurse, #2]
Identifying psychosocial aspects and supportive needs in cancer care	*"Then you ask: 'How is it with your relatives, who belongs to your family?' […] sometimes there's a bit of a question mark over their heads, like: why is all this coming up now? What do they want to know from me? And one feels a bit intrusive, so you have to explain well: 'We are trying to support you in all aspects. […] And sometimes the patients react with: 'Well, I've never been asked that before, so why now all of a sudden?' This also happens sometimes."* [Psycho-oncologist, #5]
	"Some, I would say the majority [of the nursing staff], do not do this at all because it is difficult to bring it up. In the initial phase, I diligently wrote a guide on how to conduct such conversations, but then I realized that no one was actually doing it. I asked many people: 'Why aren't you doing this?' and they said, 'Well, I have no idea how to bring it up.'" [Nurse, #7]
Advice on how to communicate with children	*"Yes, there was a case where a mother said that she had her child at home, and the child had not been in the hospital before. She told her child that she had broken her leg and was in the hospital because of that, essentially spinning a bit of a story. I told the mother that I felt this might not be the best approach and that she should perhaps consider talking to the larger family and the child. I also realized that I might not be well-equipped to offer the ideal advice in that situation."* [Nurse, #7]
	"I tell them [the patients] that the children actually always notice when something is wrong, so you can't keep it from the children. […] the children might misunderstand and think they've done something wrong […]. So, I try to encourage them [the patients] to talk about it openly or to find a way to tell the children. They don't have to say: "I'm dying", they can also say: "I have to go to hospital a lot for a while and have to get treatment […] ", so I don't communicate big death fantasies with the children, but - well, I try to give them a bit of, I don't know, concrete advice on what to do, although of course I'm not a specialist in that either." [Physician, #2]
Referral to specialized support services	*"And everyone on the team has the right to bring it [referral to a specialized support service] up with the patient. So if the nurses feel that they need to ask, they don't have to, but instead, we give them the flyer [to specialized support service] and say, 'You know, I feel this could be beneficial for you.' Sometimes, I haven't really addressed it, thinking everything is okay. However, the nurse still gave it to them because she had the impression (…)."*[Physician, #4]
	"[…] to just hand out the information [about a

(continued on next page)

Table 2 (*continued*)

Representative quotes for sub-categories	
	specialized support service], even if it's just a brochure […] because often this flood of information is there at the end of the day." [Nurse, #3]
Communication with relatives	*"I have conversations with them about my experiences, recommending that they communicate everything directly and involve the child in the process. I also offer to make time for a conversation where I can speak with the child alone if desired. […] However, these are only the older ones, not with a child of 4 or 5 or 6 […], but teenagers yes, they use this opportunity,"* [Physician, #1] *"Normally, children are only allowed on the ward from the age of 6, but in exceptional cases we sometimes allow a little less […]."* [Nurse, #3] *"[…] older colleagues then tend to argue like this and say: "Oh come on, he's still so small".* [Psycho-oncologist, #5]
Perceived differences between healthcare professionals	*"There are physicians who are very open about it, and I've already spoken to them about what we do from a nursing perspective. They think it's great and they already know that when it comes to more complicated care issues and SAPV [specialized outpatient palliative care], they can ask me: "How does that work, how can you arrange all that and so on?" Other physicians, on the other hand, tend to nod it off, but say: "Ok, yes, nice." But they're not that interested, so it's very different."* [Nurse, #3] *"So a bit of rethinking on the part of the physicians would be beneficial. […] So that they do not only treat the symptom, but people within their respective system."* [Psycho-oncologist, #5] *"Because you [as a physician] can't talk for an hour at that point. So, the nursing staff will come in and start the chemotherapy. It certainly varies on a personal level […] Some will take a moment to chat briefly with the patients."* [Physician, #4]
Attitudes about relevance to communicate about child- and family-related aspects	
Low relevance	
Other aspects in cancer care take priority	*"There's a lot of information exchanged in a conversation like this anyway. […] There's a lot of discussion about what happens next? How will the disease be treated? What is the prognosis? What can I expect? What support can I get? And in this setting, […] it's not one of the high-priority items on the agenda. Because there are simply some [aspects] that have to be dealt with first. And it is not so relevant for the start of the therapy, whether they have small children or not."* [Physician, #2]
Patients (need to) bring it up themselves	*"And it's often the case that the patients specifically ask about this because it's usually about household help or childcare. Otherwise, it's always more of a casual question when it comes to rehab and underage children are involved […]."* [Social Worker, #4]
Lies outside of their professional scope	"*I just don't think that's the focus [of our work].*" [Nurse, #3]
High relevance	
Integral part of cancer care	*"This is part of the conversation, asking how [the patients] want the communication with the children [about having cancer], whether the children know [already about the disease], what [supporting] services are available, which they can contact if there are difficulties."* [Physician, #3] *"[…] if you have the initial assessment or something like that, that you make a note of it somehow, so that it is included right from the start."* [Nurse, #3]
In palliative cases	"*[…] if the situation is such that you have to expect the patient to die somewhere in the foreseeable future. That would always be a reason to push in this direction [to communicate about child and family-related aspects in cancer care]."* [Physician, #2]. *"At the latest when it gets to this [palliative] point, then, then it will - then it [referral to specialized support service] will organize itself somehow. Either through us or from the family doctor or from recommendations from the family or whatever."* [Physician, #2].
Patients are younger	*"So what I've already done, when I realize I have younger patients, […] then I ask on my own initiative if there are any children so that I can give them the flyer [flyer of a specialized support service]."* [Nurse, #3].
Addressing psychological needs of children	*"Children very often associate cancer with a threat to their lives."* [Social Worker, #4].
Children have a right to know	*"And you also have to be honest with the child and include them. That is very important. Because they are also very sensitive. They sense something is wrong with you."* [Nurse, #3]. *"[…] children need to be informed too, in my view. […] And, in my experience, […], when they are informed and involved, things go much better, EVEN for the patient, who doesn't have the pressure of having to hide everything."* [Physician, #2].

reported to refer to specialized support services for families with parental cancer within the patient-provider interaction. This referral often coincides with participants asking structured questions about whether cancer patients are parents of minor children, and then by providing further information. Some participants reported that especially after diagnosis and at the beginning of treatment, they experienced a kind of "*information overload*" for the patients.

Additionally, participating HCPs frequently refer patients to psychosocial services when parents want guidance on discussing cancer with their children or questioned whether their children's reactions were normal. Some participants experienced feeling inadequately prepared to address these aspects themselves, which reinforced their decision to refer patients to psychosocial services.

3.2.1.5. Communication with relatives. HCPs reported that in cancer care, relatives or family members are often involved as support for the patient, but are rarely involved in the communication with HCPs or do not join clinical visits. Specifically regarding children of cancer patients, some HCPs experienced communicating with children as they accompany their parent to appointments at the clinic, such as during chemotherapy sessions, particularly when childcare is not available. One physician pointed out to offer private conversations with patients' children to address their questions. He also shared his experience of becoming emotional, when reading children's books about cancer to them. However, most participants reported that they rarely communicate directly with children or only with older children (e.g., teenagers). Additionally, experiences with children visiting the clinical setting vary based on HCPs' personal opinions (e.g., some do not permit children in the clinic due to potential infections), clinic policies (e.g., children aged six and older are allowed to visit the ward), and the age of the HCP themselves (e.g., older colleagues may be more conservative regarding young children visiting the clinic).

3.2.1.6. Perceived differences between HCPs. When exploring how HCPs perceived the interprofessional team to deal with cancer patients parenting minor children, HCPs described various experiences in communicating about child- and family-related aspects differing

between both, the professionals (e.g., psycho-oncologists vs. physicians) and individuals (e.g., between physicians), their level of experience as well as organizational barriers (e.g., time). One physician expressed his limitations discussing these aspects with patients due to limited time as a physician, however pointing out that he experienced that some nurses take their time for brief conversations with patients discussing these aspects during nursing tasks, e.g. starting the chemotherapy.

3.2.2. Attitudes about relevance to communicate about child- and family-related aspects

HCPs' attitude about the relevance of discussing child- and family-related aspects in routine cancer care varied greatly, ranging from very low relevance to viewing it as highly prioritized. When exploring how relevant the aspect in cancer care should be, some HCPs felt that this could not be answered in general, but is rather very individual and dependent on many factors. This variation is greatly influenced by opinions about what is important in cancer care, patient's own behavior, patient's disease status or age of children.

3.2.2.1. Low relevance. HCPs who view child- and family-related aspects as having low relevance in cancer care emphasize various factors, which can be summarized in three sub-categories. First, they believe ***other aspects of cancer care take priority***, such as sharing (medical) information or choice of treatment, rather than addressing the patient's role as a parent. Second, some participants expressed that these concerns should only be discussed if the ***patient brings it up him-/herself***, seeing little need to address them proactively. Lastly, several HCPs felt that addressing child- and family-related aspects ***lies outside their professional scope***, assuming that other specialists, such as psycho-oncologists, would address these aspects.

3.2.2.2. High relevance. HCPs who view the inclusion of child- and family-related aspects as highly relevant in cancer care identified several factors, which can be summarized in 5 sub-categories. First, many believe these aspects should be an ***integral part of cancer care***, though some feel they are not sufficiently incorporated, suggesting they should be included from the initial assessment. For example, one nurse mentioned that it should play a bigger role and another mentioned it should be included in the initial assessment. Second, ***in palliative cases***, HCPs see this integration as essential, as family dynamics become even more critical. Third, if HCPs treat ***younger patients***, who are more likely to have minor children, some HCPs find the inclusion of these aspects particularly relevant. Fourth, ***addressing the psychological needs of children*** is cited as a strong reason for including family-related concerns in care. Finally, many HCPs argue that ***children have a right to know*** about their parent's illness, as open communication can improve both the psychological coping of children and the well-being of the patient.

4. Discussion and conclusion

4.1. Discussion

To our knowledge, this is the first study analyzing HCPs' experiences and views on communicating about child- and family-related aspects in cancer care in Germany.

The findings highlight the diverse experiences of HCPs and their distinct attitudes regarding the importance of these communications. Factors influencing these attitudes include patient diagnosis and disease status (e.g., palliative care), structural challenges (e.g., screening for minors), and individual characteristics (e.g., patient age and profession). HCPs who viewed child and family-related aspects as less relevant tended to prioritize other medical concerns, while HCPs recognizing their importance emphasized them in palliative situations, for younger patients, and in addressing children's psychological needs.

Our findings align with previous studies focusing on the communication practices of nurses [39,40] or experiences of HCPs communicating with seriously-ill or palliative parents in end-of-life scenarios [17,22,41–43]. Results on identifying cancer patients parenting minor children indicate that experiences vary depending on the clinical setting (outpatient vs. inpatient) and implementation of routine screening for parental status. If HCPs systematically screen for parental status, parental need for specific supportive services comes up more naturally in conversations, often followed by handing a flyer or additional information. Hence, systematic registration of minor children in medical record systems supports HCPs in identifying seriously-ill parents [17].

Our findings suggest that HCPs trained in (psycho-)social disciplines may have greater confidence and skills in identifying psychosocial aspects and needs of cancer patients parenting minor children. This is not surprising, as education of psychosocial staff differs from that of nurses or physicians, focusing primarily on identifying psychosocial aspects in patient care. In contrast, while nurses and physicians also inquire about child- and family-related aspects, they tend to experience higher levels of uncertainty and express concerns about "not being specialists." These experiences align with other studies indicating that HCPs often lack confidence and feel inadequately prepared for these conversations [17,22,40,44], underscoring the need for specific communication training to enhance their knowledge, skills, and confidence.

A recurrent theme in our findings was the belief among some HCPs that their roles do not include advice on communication regarding parental aspects. This perception aligns with the results of several other studies. For instance, Hanna et al. [22] noted that HCPs in acute settings believed parental needs at the end of life would be managed by community teams, while Dalton et al. [24] found that family dynamics were rarely discussed, as it was assumed that other staff, typically nurses, would handle such matters. This trend shows that responsibility for family-related communication is often deferred to others in the healthcare system. While nurses are viewed [15,45] as willing and capable of managing the psychosocial care of cancer patients with minor children [40], they often struggle with traditional nursing emphasizing task orientation over psychosocial support [40,46,47]. Engaging in psychosocial care presents emotional challenges for clinicians, including coping with distress [17,20] and the risk of burnout or compassion fatigue [48]. As mentioned previously, there are various barriers to providing effective psychosocial care to cancer parents [17,20,22,24,39–41]. Furthermore, HCPs who do not perceive themselves as responsible for addressing psychosocial issues are less likely to engage in discussions about them [49]. Training in relevant communication skills may not only help protect HCPs from compassion fatigue and burnout [50–52], but also raise awareness about their roles and responsibilities, emphasizing the need for interdisciplinary CSTs in accordance with IPEC competencies (i.e., roles and responsibilities) [53].

Participants reported frequent referrals to specialized support services for families affected by parental cancer. The frequency of referrals among participants may reflect the availability of such services in the Hamburg area, which is not representative for most of Germany, where psychosocial support is often scattered and limited [54]. To our knowledge, no data of referral rates for specialized support services in Germany exists; hence, lower referral rates in rural areas might significantly affect support availability. Other studies have shown significant disparities in service availability across settings, particularly in the outpatient sector and rural areas [55,56]. Furthermore, a cross-sectional study in Germany found that approximately 22 % of patients have received recommendations for psycho-oncological care from physicians during their cancer diagnosis and treatment [57]. These findings suggest that referral rates for families dealing with parental cancer likely mirror those observed in regular psycho-oncological care, with disparities in availability and access. Promoting the availability and distribution of specific resources, like booklets or informational materials regarding parental cancer, could enhance HCPs' communication about these aspects [2,19], especially when psychosocial support services are lacking.

The involvement of relatives including children in cancer care is important and recommended by the German cancer guidelines, which advocate informing all involved about psychosocial support services [58]. Yet, our findings reveal great variations in HCPs' experiences when involving minor children in cancer care depending on children's age, HCPs' individual attitudes and clinical protocols. Consistent with the findings of Golsäter et al. [39] and Karidar and Glasdam [43], our study shows that relatives and children are rarely involved in cancer care, as participating HCPs tend to focus on the patient rather than addressing the family as a whole. Additionally, some participants perceived the integration of child- and family-related aspects in cancer care as low, prioritizing other aspects (e.g., treatment decisions). HCPs who proactively engage in communicating with children believe that children have a right to be informed and demonstrate high commitment and individual characteristics. Our findings align with other research, indicating that HCPs prioritize physical aspects of care over psychological [17,59]. While this focus of care is understandable, especially considering the strong emphasis on understanding the diagnosis and subsequent steps, it is important to recognize that parenting responsibilities may influence decision-making from early to advanced cancer [60–62].

Our qualitative analysis shows that HCPs found it especially important to include child- and family-related aspects in cancer care when a parent's cancer is palliative. Previous studies have primarily examined HCPs' communication experiences during advanced stages of a parental disease [17,22,42].

Parents are often uncertain how, what and when to communicate with their children about the disease [3,8,11], and minor children of cancer patients are at higher risk of distress and may develop emotional and/or behavioral difficulties [63–65]. HCPs in oncology are ideally positioned to identify cancer parents and provide basic support in parent-child communication [66], ideally referring them to the available specialized support services if necessary [67–69]. However, Dencker et al. [17] also found that HCPs tend to avoid asking about cancer patients' minor children due to their own distress and try to maintain a professional distance when a parent is dying.

Overall, it is crucial to sensitize HCPs about the importance of parent-child communication in cancer care and equip them with basic knowledge, communication skills and organizational resources to provide family-centered care [23,70]. So far, few interventions specifically addressing HCPs on the subject of parental cancer have been developed and evaluated [23], and none were available in Germany until recently [34].

Results must be interpreted with caution due to several limitations. First, the sample size was relatively small (n = 20). Second, a significant proportion of participants worked in gynecology, which may have influenced results, as this field involves more encounters with parental-related issues, since breast cancer is the most common cancer among women in this age group in Germany. Third, recruitment was limited to the Hamburg area, which has extensive psychosocial support services and established healthcare networks. This urban context does not represent Germany. Consequently, findings may not apply to settings with different demographic and resource characteristics. Fourth, professionals in oncology care vary across countries. For example, nurses in Germany typically have different responsibilities than those in the U.S. or the Netherlands, engaging less in psychosocial care. In Germany, this care is predominantly provided by psychologists or psycho-oncologists, affecting the generalizability of the findings. Fifth, a notable limitation is the time gap between data collection and publication, primarily due to personal feasibility. Despite this delay, we believe that the perspectives of various HCPs in Germany on child- and family-related aspects are underrepresented in existing literature. Therefore, our findings remain relevant, as previous research has primarily focused on nurses' communication practices [39,40], HCPs' experiences in end-of-life scenarios [17,22,41–43], or patient experiences [15]. Finally, many findings rely on self-reported practices, which may not accurately reflect actual behaviors, necessitating caution in drawing conclusions about HCPs' communication practices.

4.2. Conclusion

The findings highlight the complex experiences and varying attitudes of HCPs regarding the communication of child- and family-related aspects in cancer care. While some HCPs play an important role in identifying and supporting cancer patients parenting minor children, others do not incorporate these aspects due to various factors, such as patient diagnosis, structural challenges, lack of confidence and other individual characteristics. Our results also indicate that some HCPs perceive addressing child- and family-related aspects as outside their professional scope, despite recognizing their importance, particularly in palliative care. Additionally, a lack of systematic screening for parental status and prioritization of medical aspects, hinder some HCPs to start conversations about cancer patients' concerns and needs related to their minor children.

4.3. Practice implications

This qualitative study underscores the relevance of systematically integrating family-centered cancer care across all settings and healthcare professions, as currently experiences and attitudes vary greatly among participants.

In practice, integrating questions related to parenthood and family needs into medical record systems may facilitate systematic referrals to specialized support services. As some participants reported lack of confidence and skills to initiate conversations about child- and family-related aspects, targeted training programs are needed to enhance HCPs' a) understanding of the significance of integrating psychosocial aspects of parental cancer, and b) their communication competencies to address child- and family-related aspects. Additionally, emphasizing interprofessional collaboration, specifically the competency "role and responsibilities" is crucial, as some HCPs viewed addressing child- and family-related aspects as someone else's responsibility. This necessitates the development and evaluation of training programs that include interprofessional collaboration when addressing psychosocial issues.

Further qualitative studies should explore the barriers HCPs encounter in implementing family-centered care, informing the development of effective interventions. Additionally, incorporating direct observations alongside self-reported data could provide a more comprehensive understanding of HCPs' actual communication behaviors in practice.

List of Abbreviations

HCP	healthcare professional
HCPs	healthcare professionals
CST	Communication skills training
WF	Wiebke Frerichs
LI	Laura Inhestern
LJ	Lene Marie Johannsen
VM	Viktoria Müller

Ethical approval statement

This study is part of a larger study that was approved by the Local Psychological Ethics Committee of the Center for Psychosocial Medicine at the University Medical Center Hamburg-Eppendorf, Hamburg, Germany (approval number LPEK-001).

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CRediT authorship contribution statement

Lene Marie Johannsen: Writing – review & editing, Methodology, Formal analysis. **Corinna Bergelt:** Writing – review & editing, Supervision, Funding acquisition, Conceptualization. **Wiebke Frerichs:** Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Laura Inhestern:** Writing – review & editing, Supervision, Project administration, Funding acquisition, Data curation, Conceptualization.

Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the author Wiebke Frerichs used ChatGPT-3.5 in order to improve readability and language of the work. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

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.

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Disclosure of potential conflicts of interest

The authors declare that they have nothing to disclose.

Consent to participate

We obtained written informed consent from all healthcare professionals who participated in the study. Study participation was voluntary.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2025.108666.

Data availability statement

Data is only available on reasonable request.

References

[1] Inhestern L, et al. Estimates of prevalence rates of cancer patients with children and well-being in affected children: a systematic review on population-based findings. Front Psychiatry 2021;12:765314.
[2] Schiena E, et al. An exploratory needs analysis of parents diagnosed with cancer. Aust Soc Work 2019;72(3):325–35.
[3] Visser A, et al. The impact of parental cancer on children and the family: a review of the literature. Cancer Treat Rev 2004;30(8):683–94.
[4] Semple CJ, McCaughan E. Family life when a parent is diagnosed with cancer: impact of a psychosocial intervention for young children. Eur J Cancer Care (Engl) 2013;22(2):219–31.
[5] Romare Strandh M, et al. Psychosocial interventions targeting parenting distress among parents with cancer - A systematic review and narrative synthesis of available interventions. Crit Rev Oncol Hematol 2023;191:104119.
[6] Johannsen L, et al. The impact of cancer on the mental health of patients parenting minor children: A systematic review of quantitative evidence. Psychooncology 2022.
[7] Hailey CE, et al. Communication with children about a parent's advanced cancer and measures of parental anxiety and depression: a cross-sectional mixed-methods study. Support Care Cancer 2018;26(1):287–95.
[8] Semple CJ, McCance T. Parents' experience of cancer who have young children: a literature review. Cancer Nurs 2010;33(2):110–8.
[9] Chen R, et al. Impact of parental cancer on IQ, stress resilience, and physical fitness in young men. Clin Epidemiol 2018;10:593–604.
[10] Nilsson ME, et al. Mental health, treatment preferences, advance care planning, location, and quality of death in advanced cancer patients with dependent children. Cancer 2009;115(2):399–409.
[11] Fearnley R, Boland JW. Communication and support from health-care professionals to families, with dependent children, following the diagnosis of parental life-limiting illness: A systematic review. Palliat Med 2017;31(3):212–22.
[12] Sinclair M, et al. Maternal breast cancer and communicating with children: A qualitative exploration of what resources mothers want and what health professionals provide. Eur J Cancer Care (Engl) 2019;28(6):e13153.
[13] Grant L, et al. Cancer and the family: assessment, communication and brief interventions-the development of an educational programme for healthcare professionals when a parent has cancer. BMJ Support Palliat Care 2016;6(4):493–9.
[14] Semple CJ, McCance T. Experience of parents with head and neck cancer who are caring for young children. J Adv Nurs 2010;66(6):1280–90.
[15] Johannsen L, et al. Exploring the perspectives of cancer patients parenting minor children: A qualitative study on family-centered cancer care experiences. Patient Educ Couns 2023;117:107989.
[16] Dencker A, et al. Disrupted biographies and balancing identities: A qualitative study of cancer patients' communication with healthcare professionals about dependent children. Eur J Cancer Care 2019;28(2):e12991.
[17] Dencker, A., et al., *A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children*. 2017.
[18] Turner J, et al. Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: evaluation of an educational intervention. Eur J Cancer 2009;45(10):1798–806.
[19] Konings S, McDonald FEJ, Patterson P. Supporting parents impacted by cancer: Development of an informational booklet for parents with cancer who have adolescent and young adult children. Psycho-Oncol 2020;29(12):2101–4.
[20] Heynemann S, Philip J, McLachlan S-A. An exploration of the perceptions, experience and practice of cancer clinicians in caring for patients with cancer who are also parents of dependent-age children. Support Care Cancer 2021;29(7):3895–902.
[21] Ernst JC, et al. Use and need for psychosocial support in cancer patients. Cancer 2013;119(12):2333–41.
[22] Hanna JR, et al. Providing care to parents dying from cancer with dependent children: Health and social care professionals' experience. Psychooncology 2021;30(3):331–9.
[23] Frerichs W, et al. Child- and family-specific communication skills trainings for healthcare professionals caring for families with parental cancer: A systematic review. PLOS ONE 2022;17(11):e0277225.
[24] Dalton L, et al. Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent. Lancet 2019;393(10176):1164–76.
[25] Ledford H. Why are so many young people getting cancer? What the data say. Nature 2024;627(8003):258–60.
[26] Fearnley R, Boland JW. Parental life-limiting illness: what do we tell the children? Healthc (Basel) 2019;7(1).
[27] Uitterhoeve RJ, et al. The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature. Eur J Cancer Care (Engl) 2010;19(4):442–57.
[28] Moore PM, et al. Communication skills training for healthcare professionals working with people who have cancer. Cochrane Database Syst Rev 2018;7(7):Cd003751.
[29] Damschroder LJ, et al. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci 2009;4:50.
[30] Fernandez ME, et al. Intervention Mapping: Theory- and Evidence-Based Health Promotion Program Planning: Perspective and Examples. Front Public Health 2019;7:209.
[31] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005;15(9):1277–88.
[32] O'Brien BC, et al. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014;89(9):1245–51.
[33] Inhestern L, et al. Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot study. BMJ Open 2019;9(10):e032778.
[34] Johannsen LM, et al. Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study. Psycho-Oncol 2023;32(10):1567–77.

[35] Dresing, T. and T. Pehl, *f4tanskription software* d.d.p. GmbH, Editor., dr. dresing & pehl GmbH: Marburg, Germany.
[36] Dresing, T. and T. Pehl, *Praxisbuch Interview, Transkription & Analyse. Anleitungen und Regelsysteme für qualitativ Forschende*. 6th ed. 2015, Marburg: Eigenverlag.
[37] Kuckartz, U., *Qualitative Inhaltsanalyse. Methoden, Praxis, Computerunterstützung*. 4th ed. 2018, Weinheim, Basel: Beltz Juventa.
[38] Romer, G., C. Bergelt, and B. Möller, Kinder krebskranker Eltern. *Manual zur kindzentrierten Familienberatung nach dem COSIP-Konzept*. Vol. 1. 2014, Göttingen, Germany: Hogrefe.
[39] Golsäter M, et al. Are children as relatives our responsibility? - How nurses perceive their role in caring for children as relatives of seriously ill patients. Eur J Oncol Nurs 2016;25:33–9.
[40] Turner J, et al. Oncology nurses' perceptions of their supportive care for parents with advanced cancer: challenges and educational needs. Psychooncology 2007;16(2):149–57.
[41] Steiner V, et al. Hospital parenting support for adults with incurable end-stage cancer: multidisciplinary health professional perspectives. Health Soc Work 2021;46(4):289–98.
[42] Franklin P, et al. Health and social care professionals' experiences of supporting parents and their dependent children during, and following, the death of a parent: A qualitative review and thematic synthesis. Palliat Med 2019;33(1):49–65.
[43] Karidar H, Glasdam S. Inter-professional caring for children who are relatives of cancer patients in palliative care: perspectives of doctors and social workers. Br J Soc Work 2019;49(3):595–614.
[44] Arber A, Odelius A. Experiences of oncology and palliative care nurses when supporting parents who have cancer and dependent children. Cancer Nurs 2018;41(3):248–54.
[45] Fernández-Feito A, et al. Exploring psychosocial needs of patients with cancers through the lens of the physicians and nurses: a qualitative study. J Nurs Manag 2024;2024(1):2175517.
[46] Chen CS, et al. Nurses' perceptions of psychosocial care and barriers to its provision: a qualitative study. J Nurs Res 2017;25(6):411–8.
[47] Fernández-Basanta S, Lois-Sandá L, Movilla-Fernández M-J. The link between task-focused care and care beyond technique: A meta-ethnography about the emotional labour in nursing care. J Clin Nurs 2023;32(13-14):3130–43.
[48] Xie W, et al. The levels, prevalence and related factors of compassion fatigue among oncology nurses: a systematic review and meta-analysis. J Clin Nurs 2021;30(5-6):615–32.
[49] Ryan H, et al. How to recognize and manage psychological distress in cancer patients. Eur J Cancer Care (Engl) 2005;14(1):7–15.
[50] Gribben JL, et al. A cross-sectional analysis of compassion fatigue, burnout, and compassion satisfaction in pediatric critical care physicians in the United States. Pedia Crit Care Med 2019;20(3):213–22.
[51] Sengupta M, et al. Art of breaking bad news: A qualitative study in Indian healthcare perspective. Indian J Psychiatry 2022;64(1):25–37.
[52] Wert K, et al. Communication Training Helps to Reduce Burnout During COVID-19 Pandemic. Health Serv Res Manag Epidemiol 2023;10. 23333928221148079.
[53] IPEC. *IPEC core competencies for interprofessional collaborative practice.* Washington, DC: Interprofessional Education Collaborative; 2023.
[54] Ernst JC, et al. Psychosoziale Versorgung von Kindern mit einem an Krebs erkrankten Elternteil – Eine Bestandsaufnahme spezifischer Versorgungsangebote in Deutschland. Psychother Psychosom Med Psychol 2011;61(09/10):426–34.
[55] Ihrig A, et al. Psychosoziale Krebsberatungsstellen in Deutschland. Prävention und Gesundhörderung 2024.
[56] Schulz, H., C. Bleich, and C. Bokemeyer, *Psychoonkologische Versorgung in Deutschland*. 2018, Deutschland: Bundesweite Bestandsaufnahme und Analyse. Wissenschaftliches Gutachten im Auftrag des Bundesministeriums für Gesundheit. ⟨https://www.bundesgesundheitsministerium.de/service/publikationen/details/psychoonkologische-versorgung-in-deutschland-bundesweite-bestandsaufnahme-und-analyse.html⟩.
[57] Ernst J, et al. Doctor's recommendations for psychosocial care: Frequency and predictors of recommendations and referrals. PLoS One 2018;13(10):e0205160.
[58] Deutsche Krebsgesellschaft, A.W.M.F.Psychoonkologische Diagnostik, Beratung und Behandlung von er-wachsenen Krebspatient*innen, Langversion 2.1. 2023 [cited 2024 12–05]; Available from: https://www.leitlinienprogramm-onkologie.de/leitlinien/psychoonkologie/.
[59] Towers R. Providing psychological support for patients with cancer. Nurs Stand 2007;22(12):50–7. quiz 58.
[60] Park EM, et al. Parenting while living with advanced cancer: A qualitative study. Palliat Med 2017;31(3):231–8.
[61] Duric V, Stockler M. Patients' preferences for adjuvant chemotherapy in early breast cancer: a review of what makes it worthwhile. Lancet Oncol 2001;2(11):691–7.
[62] Check DK, et al. Concerns underlying treatment preferences of advanced cancer patients with children. Psychooncology 2017;26(10):1491–7.
[63] Morris JN, Martini A, Preen D. The well-being of children impacted by a parent with cancer: an integrative review. Support Care Cancer 2016;24(7):3235–51.
[64] Osborn T. The psychosocial impact of parental cancer on children and adolescents: a systematic review. Psychooncology 2007;16(2):101–26.
[65] Thastum M, et al. Prevalence and predictors of emotional and behavioural functioning of children where a parent has cancer: a multinational study. Cancer 2009;115(17):4030–9.
[66] Semple CJ, et al. Parent's with incurable cancer: 'Nuts and bolts' of how professionals can support parents to communicate with their dependent children. Patient Educ Couns 2022;105(3):775–80.
[67] Inhestern L, et al. Psychosocial Interventions for Families with Parental Cancer and Barriers and Facilitators to Implementation and Use - A Systematic Review. PLoS One 2016;11(6):e0156967.
[68] Alexander E, et al. A systematic review of the current interventions available to support children living with parental cancer. Patient Educ Couns 2019;102(10):1812–21.
[69] Geertz W, et al. Supportive and psychosocial peer-group interventions for children and adolescents of parents with cancer: A systematic review. Patient Educ Couns 2023;114:107844.
[70] Sheehan S, et al. A systematic review of educational interventions to equip health and social care professionals to promote end-of-life supportive care when a parent with dependent children is dying with cancer. Semin Oncol Nurs 2023;39(5):151474.

11.5. Publication 5 – Development and psychometric assessment of Study 4 [Impact-Factor: 2.7 | UKE-Score: 20.3]

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Title:

The German version of the self-efficacy questionnaire (SE-12-G) in a sample of healthcare professionals: Translation and psychometric properties

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Abstract

Background: Effective and patient-oriented communication is essential for healthcare professionals (HCPs) to deliver high-quality care. Assessing communication skills training effectiveness relies on validated measures, such as the Self-Efficacy Questionnaire (SE-12). Yet, a validated German version is lacking. Thus, we aimed to translate and adapt the SE-12 into German and assess its psychometric properties.

Methods: We translated the original SE-12 into German using the team translation protocol, adapted it to our context and added a subscale on importance of communication skills, resulting in the SE-12-G with two subscales (confidence and importance-scale). We conducted cognitive interviews with six HCPs to assess the comprehensibility of the SE-12-G. Afterwards, n=152 HCPs completed the SE-12-G at two measurement time-points. We descriptively analyzed the completion rate as indicator for acceptance, reliability (Cronbach's α) and item characteristics (i.e., item difficulties, corrected item-total correlations, inter-item correlation). A confirmatory factor analysis was performed including three a priori hypothesized models including one that represents the factor structure performed by the authors of the original version of the SE-12.

Results: Translation and comprehensibility assessment of the German version of the SE-12-G showed high face and content validity through the cognitive interviews. Completion rate exceeded 98% for all items. Mean item difficulty across all items and subscales was 0.79, (ranging between 0.71 and 0.97), inter-item correlations ranged between 0.02 and 0.73 for the confidence-scale and between 0.044 and 0.533 for the importance-scale. Ceiling effects were present for half of the items on the confidence-scale, and for all items on the importance-scale. Internal consistency yielded a Cronbach's α of 0.88 for the confidence-scale and 0.83 for the importance-scale. Confirmatory factor analysis supported a one-factor structure for both subscales of the SE-12-G.

Conclusion: The translated and adapted German version of the SE-12 shows good acceptance and reliability. Similarly to the original version, we found high ceiling effects in some items. Compared to the original factors structure, in our sample a one-factor structure was identified for both subscales.

The SE-12-G should be evaluated in further studies and modification of some items should be considered.

Trial registration:

DRKS-00015794

Keywords:

Psychometrics, self-efficacy, communication, healthcare professionals, medical education, cancer, oncology, communication skill training, family-centered care

INTROUCTION

Effective and patient-oriented communication is essential for healthcare professionals (HCPs) to deliver high-quality care to patients and their relatives (1, 2). Good patient-provider communication can foster trust and rapport (3-5) and can also improve patient-relevant outcomes (e.g. satisfaction (6), health (7), understanding (8, 9), stress (10)). Moreover, it can reduce HCPs' stress experience and emotional burnout and increase job satisfaction (1, 8). Reviews show that HCPs can be trained to increase their communication competencies through communication skills trainings in different clinical settings (1, 11, 12). One central evaluation outcome of communication skills trainings is HCPs' self-efficacy in communication skills (12-14). In context of healthcare communication, self-efficacy can be defined as one's belief in one's own communication skills to handle certain situations when communicating with patients and/or their relatives.

Despite the importance of HCPs' self-efficacy for the evaluation of communication skills trainings (12), only a few validated self-reported measures exist (15). The majority of measures relies on self-constructed questionnaires with limited validity and reliability (12).

A short and specific measure of self-efficacy, that is applicable to various clinicians, is the self-efficacy questionnaire (SE-12) developed by Axboe et al. (15). The SE-12 is available in Danish, English, Greek, Korean and Spanish (16-18) and measures self-efficacy of clinicians in their clinical communication

skills. The original version is a 12-item, unidimensional instrument developed to assess self-reported self-efficacy in physicians and nurses in Denmark before and after participating in a communication skills training. The 12 items represent the key communications skill components of the Calgary Cambridge Guide (19). Axboe and colleagues (15) found the SE-12 to be both comprehensive and comprehensible and a reliable and partly valid instrument, to assess the self-efficacy of clinical communication skills. The original SE-12 has been psychometrically tested by Axboe and collegues, revealing high internal consistency with a Cronbach's α of 0.95 (range, 0.94-0.95) and acceptable test-retest reliability for the complete scale, with an ICC agreement of 0.71 (range, 0.66-0.77), with ceiling effects evident in 9 of the 12 items (15). Since its development, the SE-12 has been used, translated or been adapted for various studies (16, 20-22). Two of these studies added an additional scale to assess the perceived importance of each item (19, 20). Currently, there is no psychometrically tested instrument in German to assess HCPs' self-efficacy in communicating with patients.

Therefore, we translated and adapted the original SE-12 scales into German and investigated the psychometric properties of the translated German version (SE-12-G) in a sample of German HCPs.

METHODS

Study design and setting

The presented study is a secondary analysis of data from a randomized controlled pilot-study focusing on communication in the context of parental cancer (23, 24), which was conducted at the Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Germany. The study was registered within the German Clinical Trial Register (DRKS-00015794) and approved by the Local Psychological Ethics Committee of the Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf, Germany (LPEK-001).

The original SE-12 measure

The SE-12 measures self-efficacy of clinicians in their clinical communication (15). The original version is a unidimensional instrument with 12 items using a 10-point response scale (1: very uncertain, 10: very certain) to measure confidence in their communication skills including an additional „not relevant“ option (15). Each question starts with the words “How certain are you that you are able to successfully …” followed by a specific communication skill (15). Sum score of the 12 items yields the SE-12 scale with higher scores indicating higher self-efficacy of clinical communication skills. The SE-12 has been adapted by adding a further scale measuring the perceived importance of each item by including a 5-point-scale (1: not important at all to 5: very important) (20) (19), so far without reporting on the psychometric properties of this additional scale.

Translation and adaptation of the SE-12-G

In order to assess self-efficacy of healthcare professionals in their communication competencies, the original SE-12 questionnaire (15) was translated into German following the TRAPD team translation protocol (25). The TRAPD (Translation, Review, Adjudication, Pretesting and Documentation) method has been endorsed within the Guideline for Best Practice in Cross-Cultural Surveys (26) complying with best practice translation research (27). An Excel spreadsheet was developed to assist with the translation and review process for each member of the research team and to document the process. Two team members (WF having a bilingual health science and physical therapy background, MLN a psychology background) independently translated the English version of the SE-12. A third blinded team member (CB) with experience in survey translation reviewed these translations, selecting one version or creating a new one as needed. Finally, all authors discussed the translations, until a consensus on a final version of the SE-12-G was reached. As a next step, the newly developed SE-12-G version was pretested by conducting cognitive interviews to assess comprehensibility and feasibility of the measure. Additionally, we adapted it by including a second scale, the perceived

importance-scale, rating the same 12 items on a 5-point-Likert-scale ('How important is it to incorporate this skill into your clinical work? 1: not important at all to 5: very important), with an additional check box 'not relevant' for both subscales all together (see Table 3 for the English items of the SE-12-G and Additional file 1 for the German SE-12-G).

In context of the randomized controlled pilot-study (23), cognitive interviews about the applied series of measures were conducted with HCPs working in oncology to assess the comprehensibility and feasibility in the context of content validity. During the cognitive interviews the think-aloud method was combined with the verbal probing technique (28) to review opinions on certain phrases, distinct words and their meanings for various HCPs and certain skills in daily practice (e.g., comprehensive probing "What does the term 'non-verbal behavior' mean to you?" or selection probing "When would you choose the answer 'not relevant'"?). Interviews were audio-recorded and supported by handwritten protocols. After the interviews comments and suggestions from the material was discussed (WF, LJ, LI, CB), however no further adaptions to the SE-12-G were necessary.

Psychometric assessment

Participants and data collection

As this study is a secondary analysis of data from a randomized controlled pilot-study, study participants were part of a sample of various HCPs in Germany participating in this pilot- study. HCPs were included if they were working in oncology (independent of setting, profession or amount of professional experience in oncology) (23). They were recruited by e-mail or mail through existing networks, clinics and lists of cooperation partners. Participants did not receive any incentives for participation and participation was voluntary. In the pilot-study, HCPs received a paper & pencil baseline questionnaire including the SE-12-G and were randomized by group stratification after returning the baseline questionnaire. The post-training questionnaire (t1) was sent after training and in the waitlist-control group 6 weeks after the return of the baseline questionnaire.

The SE-12-G was applied in a series of measures to assess HCPs' competencies regarding child- and family-related issues in cancer care. Additionally, demographic variables (e.g., gender, age, profession, work experience with cancer patients) and experience with previous communication skills trainings were assessed.

Data collection started in September 2019 and ended in April 2021. Data were entered into SPSS (IBM SPSS Statistics, V.27) including blinded double entry of 20% for quality control.

Data analyses

Descriptive statistics using frequencies for categorical data or mean values and standard deviation (SD) for metric data were calculated to describe the sample. In the following data analysis strategies will be reported, where Table 1 gives a detailed overview on established criteria used to interpret performed data analyses.

Item analysis was performed for each subscale including calculation of item means and standard deviations (SD), corrected item-total correlations and inter-item correlations. Observed floor and ceiling effects were assessed by analyzing the distribution of participants marking the highest as well as lowest possible score per item and scale. The maximum score was 10 for the confidence-scale and 5 for the importance-scale. Item difficulty was assessed for each of the 12 items on both subscales. Internal consistency was estimated by calculating Cronbach's coefficient alpha for each scale (confidence- and importance-scale). Test-retest reliability was assessed using the data of two measurement points from participants from waitlist-control group only, calculating Spearman correlation coefficient at item level for each of the 12 self-efficacy items for each scale, and calculating Pearson correlation for the sum score of the subscales. Content validity was assessed by exploring whether the SE-12-G reflects on characteristics of participants, namely "working experience in general" and "working experience with cancer patients" (both in years), similar to Axboe et al. (15). For this purpose, we tested the relations of the confidence-scale and importance-scale to these two self-developed items by using bivariate correlations. To assess responsiveness to

change, Cohen's *d* was used to assess change in both intervention groups, analyzing the effect size of the intervention, complemented by an additional t-test to determine significance. For discriminant validity, known-group differences (Kruskal-Wallis test) comparing the four HCP groups at baseline were calculated followed by post-hoc tests using the Dunn's test with Bonferroni correction for multiple comparisons. For these analyses, various data were used: for the responsiveness to change analysis, data from both intervention groups for the two measurement points (baseline and post-training questionnaire) were used; for the test-retest reliability, data from the waitlist-control group at two measurement points (baseline and 6-weeks after baseline) were used; for all other analysis only the baseline data was applied; the completion rate was calculated to assess the acceptance of the measure; the frequencies of missing data were calculated per item as well as for the overall measure and all cases; for all other calculations, missing data were replaced with item means. Cases were excluded if more than 30% of the SE-12-G items were missing (29).

To evaluate the factorial validity of the SE-12-G, we conducted a confirmatory factor analysis (CFA) (30, 31) (32). To test assumptions for performing a factor analysis, Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity were calculated (33, 34). Three a priori models were hypothesized: Model 1, replicating the one-dimensional factorial structure of the original SE-12 measure for the confidence-scale only (M1); Model 2, assuming a two-factor structure with variables from both subscales (confidence and importance) treated as continuous variables and accounting for residual covariance between each item and scales to address methodological variance (M2); and model 3, an ordinal factor model (M3a) assuming a two-factor structure with both subscales, treating importance variables as ordinal due to the non-normal distribution of the data. The third model was further fitted to check modified indices and possible correlations between items on content-level (M3b) (e.g., item 3 (… *to encourage a patient to express and discuss their problems and concerns.*) and item 5 (… *to express their thoughts and feelings.*)).

For M1 and M2 full information maximum likelihood estimates were applied (35), for M3 (a and b), the diagonally weighted least squares method, which is specifically designed for ordinal-scaled data

with robust estimation (36), was performed. Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy with values >.05 and the Bartlett's test of sphericity with values <.05 were conducted to test criteria for calculating a CFA (33, 34).

To evaluate the global fit indices, the following were included: (a) the comparative fit index (CFI) and the Tucker-Lewis index (TLI); (b) the root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR); and (c) average variance extracted (AVE) (33, 37, 38). Further, factor covariance was explored to understand the relationship between the two latent factors confidence in and importance of these 12 communication skills.

Analysis of demographic data, analysis of completion rate, item analysis was performed using SPSS (IBM SPSS Statistics, Version 29.0.1.0). CFA and model of fit indices calculations were performed using JASP (JASP Team, 2023 Version 0.18.1), an open-source software, whose analyses are written in R.

Table 1. Psychometric analyses performed.

Psychometric analyses	Criteria/Description
Item Response Distributions	Evaluates the distribution of responses for each item to identify patterns or irregularities.
Inter-Item Correlations	Assesses the degree of relationship between pairs of items. Values too close to 1 may indicate redundancy; too low values suggest lack of coherence. High inter-item correlations of above 0.80 indicate that items ask the same questions and might be redundant (33, 39).
Corrected Item-Total Correlation	Measures the relationship between each item and the total score excluding the item. Higher values indicate good item consistency. Generally, values >0.3 are considered acceptable, representing items measuring the same underlying concepts. Items with <0.30 should be considered to be removed (40).
Floor and Ceiling Effects	Identifies items where a significant portion of respondents score at the lowest (floor) or highest (ceiling) possible value. Cut-off values of >15% of respondents are considered to be high (41).
Item Difficulties	Quantifies the proportion of correct responses to an item. Ranges from 0 (most difficult) to 1 (easiest). Item difficulties are calculated by dividing item means by the maximal value of the answer range (0–4) and multiplying it with 100. Item difficulty should be near to 50%, and items should not differ much in their difficulty level (33, 42) (34)

Cronbach's α	Assesses internal consistency; values ≥ 0.70 are considered acceptable for early stages of research, with ≥ 0.80 preferred for established scales (40).
Kaiser-Meyer-Olkin (KMO) Measure	Values > 0.6 suggest adequate sample size for factor analysis (33).
Bartlett's Test of Sphericity	Tests the hypothesis that the correlation matrix is an identity matrix, indicating suitability for factor analysis. $p < 0.05$ indicates appropriateness (33).
Comparative Fit Index (CFI)	CFIs is an indicator for model fit. It ranges from 0 to 1 and higher values indicate better fit. Values above .95 indicate a good model fit (37, 43).
Tucker-Lewis Index (TLI)	Values > 0.90 suggest a good fit of the model to the data in confirmatory factor analysis (37).
Root Mean Square Error of Approximation (RMSEA)	Values ≤ 0.05 indicate a close fit, values up to 0.08 represent reasonable errors of approximation in the population (44).
Standardized Root Mean Square Residual (SRMR)	Values ≤ 0.08 are generally considered good, indicating small residuals between observed and model-implied covariances (37).
Average Variance Extracted (AVE)	Represents the average of the squared factor loadings for all observed variables associated with a particular construct with recommended values of ≥0.5 (45, 46).

RESULTS

Translation and adaptation of the SE-12-G

Both translators (WF and MLN) and the reviewer (CB) did not differ much in their translations of the items as well as the response scale. Translation differences were found for the introduction (how to best translate the word "skills") as well as single items, namely item 2 (agenda vs. themes), item 7 (adding e.g., to the examples), item 8 (by using a German synonym for empathy), item 11 (the word "shared" was translated differently) and item 12 (the word "assuring" was translated differently). Additionally, the response format word for "not relevant" differed between both translators. In summary, only the choice of single words differed between the translators without differences in meaning (e.g., the word "patient" also represents the word "client", which is often used in psycho-oncology, psycho-social and psychotherapy settings). Within the first round of team discussion (adjudication process) all authors reached consensus on a final version.

To test the German version of the SE-12 for comprehensibility, cognitive interviews with n=6 HCPs (n=2 physicians, n=2 nurses, n=2 psychologists; 50% being female) were conducted by assessing the

complete evaluation tool developed for the pilot-study (Johannsen et al. 2023). Cognitive interviews for the complete 13-page baseline questionnaire including a series of measurements lasted for about 75 minutes each. As participants had no critical feedback or comprehensibility issues on the instructions and items of the SE-12-G, no further adaptions to the final version were necessary. The final SE-12-G measure used in this study can be found in the Additional file 1, the English version is displayed in Table 3.

Psychometric assessment

Sample characteristics

Data of n=152 participants were included in this secondary data analysis. The mean age was 44.4 years (SD 11.6) with 88% being female. Most of the participants were psychologists (37.5%), followed by physicians (26.3%), nurses (18.4%) and social workers/others (17.8%). Of their professional experience working with cancer patients, most had >11 years of experience (39.1%), followed by 1-5 years (30.5%), 6-10 years (21.9%) and 8.6% less than 1 year (see Table 2).

Table 2. Sample characteristics at baseline (t0, n=152).

	Total (n = 152)
Age, M (SD) [range]	44.42 (11.6) [24-71]
Sex, n (%)	
female	134 (88.2)
male	18 (11.8)
Professional group, n (%)	
Physician	40 (26.3)
Nurse	28 (18.4)
Psychologist	57 (37.5)

	Total (n = 152)
Social Worker/Other	27 (17.8)
Workplace setting[†], n (%)	
outpatient	94 (61.8)
inpatient	84 (55.3)
self-employed/registered	25 (16.4)
other	8 (5.3)
Working experience with cancer patients, n (%)	
< 1 year	13 (8.6)
1-5 years	46 (30.5)
6-10 years	33 (21.9)
> 11 years	59 (39.1)
Amount of cancer patients per month, No. M (SD) [range], %	67.4 (33.0) [.1-100], n=143
Amount of cancer patients between 25-55 years old, M (SD) [range] in %	37.52 (22.21) [.1-100], n=131
Amount of cancer patients parenting minor children, M (SD) [range] in %	21.4 (21.9) [0-100], n=123
Marital status, n (%)	
single	54 (35.8)
married	82 (54.3)
separated/divorced	11 (7.3)
registered partnership	1 (0.7)
widowed	3 (1.9)
Participants having children, n (%)	97 (63.8)
Having participated in communication skills trainings before, n (%)	134 (88.2)

Abbreviations. M: Mean, SD: Standard Deviation; [†]Multiple answers possible

SE-12-G item analysis

Table 3 shows response distribution, distribution of participants with highest score (floor effects), acceptance, corrected item-total correlation and item difficulty of the 12 items.

Depending on the item, between 5.3% and 6.6% of the participants rated the respective item as “not relevant”. Missing values ranged from 1.3-2% per item. Considering all items, participants answered more than 98% of the SE-12-G.

Ceiling effects were present, for the confidence-scale in 6 of the 12 items (items 3, 4, 5, 7, 8, 10) with a range from 15.8% (item 10) to 30.3% (item 8) of respondents, exceeding the >15% set as limit (41) and therefore indicating high ceiling effects. Regarding the importance-scale, all 12 items present ceiling effects with a range from 54.6% (item 9 and 11) to 85.5% (item 8).

Corrected item-total correlation values for the confidence-scale ranged from 0.46 (item 4) to 0.66 (item 3), for the importance-scale values ranged from 0.34 (item 1) to 0.62 (item 10) with Items 3 for the confidence-scale and item 10 for the importance-scale suggesting stronger relationships between the items and the construct. In contrast, item 4 for the confidence-scale and item 1 for the importance-scale indicate weaker associations with the construct with correlation values of <0.30.

The mean item difficulty (Table 3) across all items was 0.79 for the confidence-scale (range 0.71-0.87) and 0.91 for the importance-scale (range 0.84-0.97) indicating that, on average, items tended to be relatively easy for participants.

Inter-item correlations (Table 4) for the confidence-scale ranged from 0.019 (item 4 and item 11) to 0.733 (item 3 and item 5), for the importance-scale from 0.044 (item 5 and item 8) to 0.533 (item 2 and item 10), indicating that item 4 and 11 lack coherence.

Table 3. Descriptive statistics of participants for the SE-12-G, response distribution, means, standard deviation, acceptance, item discrimination and item difficulty (n=139-149 healthcare professionals).

How certain are you that you are able to successfully … / How important is it to …	Scale	N	M (SD), [Min, Max]	% participants with highest score	Acceptance (number of missings, n (%))	Relevance (number of 'not relevant', n (%))	Item discrimination (corrected item-total correlation)	Item difficulty (M)
1. …identify the issues the patient wishes to address during the conversation?	C-Scale	149	7.83 (1.36), [4, 10]	8.6	2 (1.3)	1 (.7)	0.61	0.76
	I-Scale	148	4.84 (.47), [1, 5]	83.6	3 (2)		0.34	0.96
2. … make an agenda/plan for the conversation with the patient?	C-Scale	142	7.81 (1.48), [3, 10]	10.5	2 (1.3)	8 (5.3)	0.57	0.76
	I-Scale	141	4.55 (.6), [3, 5]	55.9	3 (2)		0.59	0.89
3. … urge the patient to expand his or her problems/worries?	C-Scale	148	8.51 (1.39), [4, 10]	27	3 (2)	1 (.7)	0.66	0.83
	I-Scale	149	4.78 (.46), [3, 5]	78.3	3 (2)		0.45	0.94
4. … listen attentively to the patient?	C-Scale	149	8.84 (1.28), [5, 10]	38.8	2 (1.3)	1 (.7)	0.46	0.87
	I-Scale	149	4.77 (.46), [3, 5]	76.3	2 (1.3)		0.48	0.94
5. … encourage the patient to express thoughts and feelings?	C-Scale	147	8.36 (1.34), [5, 10]	22.4	2 (1.3)	3 (2)	0.63	0.82
	I-Scale	146	4.69 (.53), [3, 5]	69.7	2 (1.3)		0.47	0.92
6. … structure the conversation with the patient?	C-Scale	146	7.44 (1.63), [3, 10]	9.9	1 (.7)	5 (3.3)	0.62	0.72
	I-Scale	146	4.35 (.72), [2, 5]	46.1	1 (.7)		0.49	0.84

7. … demonstrate appropriate non-verbal behavior (eye contact, facial expression, placement, posture, and voicing)?	C-Scale	148	8.28 (1.46), [2, 10]	17.8	2 (1.3)	2 (1.3)	0.50	0.81
	I-Scale	148	4.68 (.51), [3, 5]	68.4	2 (1.3)		0.42	0.92
8. … show empathy (acknowledge the patient's views and feelings)?	C-Scale	148	8.85 (1.02), [6, 10]	30.3	2 (1.3)	2 (1.3)	0.52	0.87
	I-Scale	148	4.87 (.36), [3, 5]	85.5	2 (1.3)		0.55	0.97
9. … clarify what the patient knows in order to communicate the right amount of information?	C-Scale	145	7.81 (1.55), [2, 10]	11.2	2 (1.3)	5 (3.3)	0.59	0.76
	I-Scale	145	4.52 (.60), [3, 5]	54.6	2 (1.3)		0.46	0.88
10. … check patient's understanding of information given?	C-Scale	144	8.31 (1.50), [2, 10]	15.8	2 (1.3)	5 (3.3)	0.57	0.79
	I-Scale	145	4.68 (.54), [3, 5]	67.8	2 (1.3)		0.62	0.92
11. … make a plan based on shared decisions between you and the patient?	C-Scale	139	7.76 (1.69), [2, 10]	13.2	3 (2)	10 (6.6)	0.55	0.75
	I-Scale	139	4.52 (.65), [2, 5]	54.6	3 (2)		0.42	0.88
12. … close the conversation by assuring, that the patient's questions have been answered?	C-Scale	148	7.70 (1.67), [2, 10]	11.2	2 (1.3)	2 (1.3)	0.56	0.75
	I-Scale	149	4.58 (.64), [2, 5]	63.8	2 (1.3)		0.50	0.90
Overall Confidence-Scale (Items 1-12)			8.11 (.95), [5, 10]	18.06	n/a	n/a	n/a	0.79
Overall Importance-Scale (Items 1-12)			4.65 (.33), [3.67, 5]	67.05	n/a	n/a	n/a	0.91

Confidence-scale (range 1-10; 1: very uncertain to 10: very certain)

Importance-scale (range 1-5; 1: not important at all to 5: very important)

Table 4. Inter-Item Correlation for the SE-12-G (n=131-132 healthcare professionals).

Confidence-scale

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10	Item 11	Item 12
Item 1	1	0.541	0.679	0.436	0.552	0.403	0.351	0.508	0.329	0.209	0.262	0.248
Item 2	0.541	1	0.451	0.334	0.422	0.525	0.228	0.35	0.264	0.366	0.326	0.312
Item 3	0.679	0.451	1	0.473	0.733	0.392	0.325	0.573	0.315	0.258	0.299	0.359
Item 4	0.436	0.334	0.473	1	0.596	0.279	0.347	0.456	0.17	0.144	0.019	0.288
Item 5	0.552	0.422	0.733	0.596	1	0.368	0.3	0.462	0.308	0.336	0.253	0.295
Item 6	0.403	0.525	0.392	0.279	0.368	1	0.278	0.308	0.512	0.446	0.473	0.399
Item 7	0.351	0.228	0.325	0.347	0.3	0.278	1	0.381	0.388	0.431	0.338	0.332
Item 8	0.508	0.35	0.573	0.456	0.462	0.308	0.381	1	0.151	0.203	0.157	0.313
Item 9	0.329	0.264	0.315	0.17	0.308	0.512	0.388	0.151	1	0.61	0.602	0.464
Item 10	0.209	0.366	0.258	0.144	0.336	0.446	0.431	0.203	0.61	1	0.533	0.413
Item 11	0.262	0.326	0.299	0.019	0.253	0.473	0.338	0.157	0.602	0.533	1	0.562
Item 12	0.248	0.312	0.359	0.288	0.295	0.399	0.332	0.313	0.464	0.413	0.562	1

Importance-scale

	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10	Item 11	Item 12
Item 1	1	0,356	0,193	0.252	0.257	0.157	0.147	0.263	0.157	0.247	0.135	0.142
Item 2	0.356	1	0.442	0.373	0.425	0.367	0.264	0.365	0.238	0.523	0.275	0.232
Item 3	0.193	0.442	1	0.227	0.521	0.289	0.17	0.361	0.152	0.331	0.07	0.277
Item 4	0.252	0.373	0.227	1	0.376	0.24	0.224	0.38	0.282	0.306	0.168	0.323
Item 5	0.257	0.425	0.521	0.376	1	0.33	0.253	0.423	0.044	0.272	0.072	0.268
Item 6	0.157	0.367	0.289	0.24	0.33	1	0.353	0.339	0.23	0.363	0.253	0.293
Item 7	0.147	0.264	0.17	0.224	0.253	0.353	1	0.373	0.23	0.278	0.217	0.211
Item 8	0.263	0.365	0.361	0.38	0.423	0.339	0.373	1	0.289	0.374	0.156	0.304
Item 9	0.157	0.238	0.152	0.282	0.044	0.23	0.23	0.289	1	0.432	0.499	0.398
Item 10	0.247	0.523	0.331	0.306	0.272	0.363	0.278	0.374	0.432	1	0.378	0.407
Item 11	0.135	0.275	0.07	0.168	0.072	0.253	0.217	0.156	0.499	0.378	1	0.385
Item 12	0.142	0.232	0.277	0.323	0.268	0.293	0.211	0.304	0.398	0.407	0.385	1

Table 5. Test-retest reliability (n=40-74 healthcare professionals).

Item How certain are you that you are able to successfully … / How important is it to …	Scale	N	*r*	95% CI
1. …identify the issues the patient wishes to address during the conversation?	C-scale	47	0.755**	.540-.863
	I-scale	47	0.415**	.053-.703
2. … make an agenda/plan for the conversation with the patient?	C-scale	44	0.481**	.154-.719
	I-scale	44	0.351*	.027-.642
3. … urge the patient to expand his or her problems/worries?	C-scale	46	0.443**	.125--700
	I-scale	46	0.381**	.017-.681
4. … listen attentively to the patient?	C-scale	47	0.639**	.344-.850
	I-scale	47	0.605**	.342-.831
5. … encourage the patient to express thoughts and feelings?	C-scale	45	0.699**	.480-.833
	I-scale	45	0.632**	.345-.833
6. … structure the conversation with the patient?	C-scale	47	0.538**	.269-.730
	I-scale	47	0.160	-.160-.464
7. … demonstrate appropriate non-verbal behaviour (eye contact, facial expression, placement, posture, and voicing)?	C-scale	46	0.491**	.202-.742
	I-scale	46	0.349*	.004-.645
8. … show empathy (acknowledge the patient's views and feelings)?	C-scale	46	0.659**	.439-.819
	I-scale	46	0.327*	-.092-.697
9. … clarify what the patient knows in order to communicate the right amount of information?	C-scale	45	0.601**	.385-.765
	I-scale	45	0.421**	.139-.672
10. … check patient's understanding of information given?	C-scale	45	0.556**	.332-.726
	I-scale	45	0.412**	.954.707
11. … make a plan based on shared decisions between you and the patient?	C-scale	41	0.481**	.131-.753
	I-scale	40	0.226	-.110-.536
12. … close the conversation by assuring, that the patient's questions have been answered?	C-scale	46	0.430**	.143-.668
	I-scale	46	0.417**	.128-.700

Overall Confidence-Scale (Items 1-12)†	47	0.725**	.484-.874
Overall Importance-Scale (Items 1-12)†	47	0.726**	.479-.862

Abbreviations: C-Scale: Confidence-scale (range 1-10; 1: very uncertain to 10: very certain); I-Scale: Importance-scale (range 1-5; ; 1: not important at all to 5: very important); The correlation (two-sided) is significant at *p < 0.05, ** p < 0.001; 95% Bootstrap Confidence Interval reported in brackets; †Pearson correlation, all other items were calculated with Spearman correlation coefficient;

Internal consistency and test-retest reliability

Cronbach's alpha coefficient for SE-12-G was high with a calculated α of 0.88 for the confidence-scale and α 0.83 for the importance-scale.

The test-retest reliability at item level for the two subscales was good with estimated correlation coefficient for the 12 items for the confidence-scale being *r*=0.725 with a 95% Bootstrap Confidence Interval (BCI) of 0.484-0.874 and for the importance-scale estimated correlations of *r*=0.726 with a 95% BCI of 0.479-0.862 (Table 5). For the confidence-scale no item showed a weak correlation, 5 items showed a moderate correlation of 0.430-0.491 (item 2, 3, 7, 11, 12) and 6 items showed strong correlations ranging from 0.538-0.755 (item 1, 4, 5, 6, 8, 9, 10). For the importance-scale, two items had a strong correlation (item 4 *r*=0.605, item 5 *r*=0.632), 8 items a moderate correlation ranging from 0.327-0.421 (item 1, 2, 3, 7, 8, 9, 10, 12) and two items a weak correlation (item 6 *r*=0.160, item 11 *r*=0.226).

Convergent validity

Statistically significant but weak correlations were found between the confidence-scale and the items *working experience in general* (*r*=0.203**, range 0.043 - 0.350) and *working experience with cancer patients* (*r*=0.147**, range 0.085-0.406). No significant correlations were found for the importance-scale for *working experience in general* (*r*=.035, range -0.116 - 0.191) and *working experience with cancer patients* (*r*=0.147, range -0.093 - 0.250).

Responsiveness to change

The Cohen's *d* for the confidence-scale was 0.77 (95% CI [4.0, 5.5]), indicating a moderate to large effect size, suggesting responsiveness for change after an intervention (Table 6). For the importance-scale Cohen's *d* was 0.25 (95% CI [-.167, .275]) indicating a small effect, suggesting that this subscale shows limited sensitivity in detecting changes over time.

Table 6. Responsiveness to change.

Scale	N†	*Mdiff* (SD) [95% CI]	T	*df*	*p*	*d* [CI 95%]
Confidence-scale t1-t0	80	3.68 (0.77) [3.5, 3.8]	42.727	79	< 0.000	0.77 [4.0;5.5]
Importance-scale t1-t0	79	0.01 (0.25) [-0.4, 0.07]	0.475	78	0.636	0.25 [-.167,.275]

Abbreviations: † Intervention participants only (face-to-face and E-Learning, two measurement points, baseline (t0) and after-training participation (t1); *Mdiff,* mean difference (t1-t0); SD*,* Standard Difference; *CI,* Confidence Interval; *T, T-tests; df,* degrees of freedome; *p,* p-value*; d,* Cohen's *d* effect.

Discriminant validity

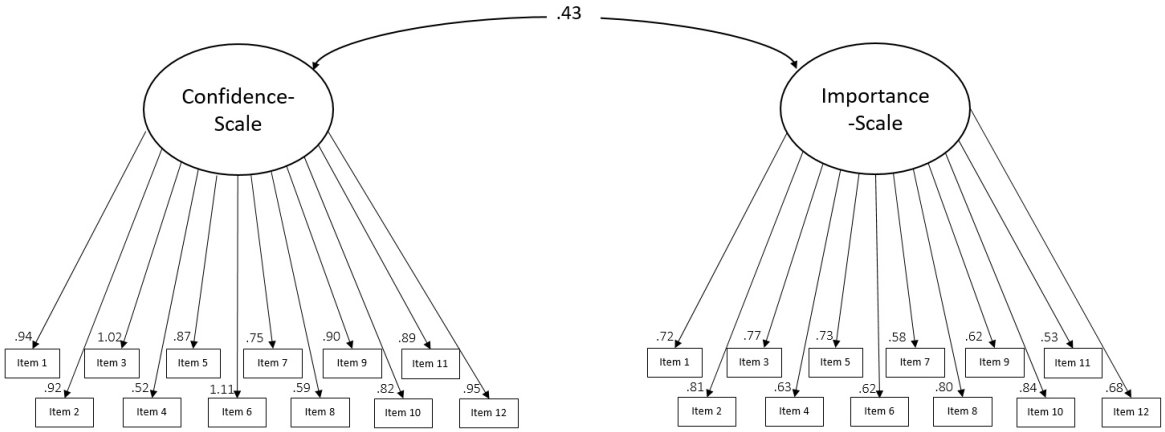
Analyses of group differences between HCP groups revealed statistically significant differences among the groups for several items of the confidence-scale (e.g., urge the patient to express his or her problems/worries, listen attentively to the patient, demonstrate appropriate non-verbal behavior, show empathy, make a plan based on shared decisions) and for two items in the importance subscale (listen attentively to the patient, encourage the patient to express thoughts and feelings). Most differences were between physicians and psychologists as well as nurses and psychologists with psychologists scoring higher in self-efficacy (Table 7).

Factor analysis

Requirements for factor analysis were met, with an adequate sample size of n=149 HCPs related to the indicators per factor (47), after three cases were excluded due to >30% missing items. Additionally, further requirements were met, with KMO measure at .0.843 and Bartlett's test of sphericity yielding X^2=829.190, p<.001 (33) (34). Model fit indices of the three a priori models are presented in Table 8. Factor reliability was satisfactory for all three models (M1: ω 0.827; M2: ω

0.891; M3a: ω 0.839 confidence and ω 0.882 importance), and factor loadings for all 12 items for both subscales were medium to high (M1: between 0.477 and 0.799 for the confidence-scale only; M2: 0.395-0.751 for both subscales; M3a: 0.405-0.810 for both subscales; M3b: 0.410-0.837)(see Figure 1 for M3b and Additional file 2 for figures of M1-3a), indicating that the presented items (communication skills) measure the underlying construct (confidence in and importance of these skills). Factor covariance for M2 and M3a was 0.426 and for M3b 0.432, indicating a moderate correlation between the two factors, affirming their distinctness as separate constructs.

Figure 1. Confirmatory factor analysis model for one-factorial structure (Model 3b).



Regarding the model fit indices, values indicated a suboptimal fit of the three assumed models (Table 8). The convergent validity of all three models was low, with higher, but still inadequate AVE values for M3a and M3b for both factors (Table 8), indicating that the latent constructs do not adequately capture the variance in its observed indicators (38).

Table 7. Discriminant validity - Known-group differences comparing the four HCP groups (n=93-98 HCPs).

Items How certain are you that you are able to successfully … / How important is it to …	Scale	$x^{2\dagger}$	PHY Mean rank	NRS Mean rank	PSY Mean rank	SW/O Mean rank	Mean difference *z* (SE) †† PHY vs NRS	PHY vs SW/O	PHY vs PSY	NRS vs PSY	NRS vs SW/O
1. …identify the issues the patient wishes to address during the conversation?	C-scale	9.630*	40.80	38.03	56.96	56.67	ns	ns	ns	ns	ns
	I-scale	3.597	45.80	46.94	52.95	46.94	ns	ns	ns	ns	ns
2. … make an agenda/plan for the conversation with the patient?	C-scale	6.381	43.84	34.40	53.53	51.19	ns	ns	ns	ns	ns
	I-scale	2.276	46.62	44.70	45.82	55.50	ns	ns	ns	ns	ns
3. … urge the patient to expand his or her problems/worries?	C-scale	11.602**	39.40	40.29	60.68	48.61	ns	ns	-21.284 (7.076)*	ns	ns
	I-scale	5.595	45.92	41.79	53.12	54.11	ns	ns	ns	ns	ns
4. … listen attentively to the patient?	C-scale	9.521	38.28	46.47	59.26	47.33	ns	ns	-20.983 (6.988)*	ns	ns
	I-scale	9.294*	41.34	59.00	48.64	53.67	-17.660 (6.134)*	ns	ns	ns	ns
5. … encourage the patient to express thoughts and feelings?	C-scale	5.893	43.48	40.62	57.18	50.03	ns	ns	ns	ns	ns
	I-scale	11.357**	42.21	38.88	57.00	50.72	ns	ns	ns	-18.118 (6.323)*	ns
6. … structure the conversation with the patient?	C-scale	1.807	48.38	39.83	50.88	48.21	ns	ns	ns	ns	ns
	I-scale	5.964	52.96	53.47	40.37	52.94	ns	ns	ns	ns	ns

7. … demonstrate appropriate non-verbal behaviour (eye contact, facial expression, placement, posture, and voicing)?	C-scale	10.728*	44.34	34.18	59.09	50.89	ns	ns	ns	-24.916 (8.061)*	ns
	I-scale	1.110	49.40	45.94	52.30	47.08	ns	ns	ns	ns	ns
8. … show empathy (acknowledge the patient's views and feelings)?	C-scale	9.688*	41.60	41.41	60.08	45.78	ns	ns	-18.479 (7.008)*	ns	ns
	C-scale	6.669	45.56	44.09	54.22	50.11	ns	ns	ns	ns	ns
9. … clarify what the patient knows in order to communicate the right amount of information?	I-scale	1.233	51.86	48.18	44.99	51.53	ns	ns	ns	ns	ns
	C-scale	2.516	54.90	47.85	45.99	45.21	ns	ns	ns	ns	ns
10. … check patient's understanding of information given?	I-scale	2.924	46.77	44.68	53.41	41.29	ns	ns	ns	ns	ns
	C-scale	1.938	48.33	42.94	47.51	53.65	ns	ns	ns	ns	ns
11. … make a plan based on shared decisions between you and the patient?	I-scale	9.990**	58.08	31.07	45.63	47.93	ns	ns	ns	27.013 (8.621)**	ns
	C-scale	2.267	52.74	42.40	45.26	46.43	ns	ns	ns	ns	ns
12. … close the conversation by assuring, that the patient's questions have been answered?	I-scale	4.886	47.14	38.50	55.92	49.61	ns	ns	ns	ns	ns
	C-scale	1.311	50.32	43.82	51.51	49.47	ns	ns	ns	ns	ns

Abbreviations:
PHY: Physician; NRS: Nurses; PSY: Psychologists; SW/O: Social Workers/Others; † Degrees of freedom = 3; †† Dunn's test with Bonferroni correction for multiple comparisons; *$p < 0.05$, **$p \leq 0.01$; ns, not significant ($p > 0.05$);

Table 8. Fit indices for the SE-12-G questionnaire.

Model	χ2	df	*P* value	CFI	TLI	RMSEA [90% CI]	SRMR	AVE
M1	268.346	54	<.001	0.712	0.648	0.163	0.106	0.364
M2	579.761	239	<.001	0.776	0.741	0.097	0.092	C: 0.396 I: 0.331
M3a	366.631	235	<.001	0.888	0.868	0.061	0.098	C: 0.357 I: 0.497
M3b	376.144	235	<.001	0.880	0.859	0.063	0.099	C: 0.359 I: 0.489

Note: M1=Axboe et al. Model, only confidence-scale; M2=The model which included confidence- and importance-scale for each 12 items applying continuous variables; M3a = The model which included confidence- and importance-scale for each 12 items, applying ordinal variables for the importance-scale; M3b = like M3a but additional modifications for assumed residual covariances for items 3 and 5 as well as 9 and 10.

Abbreviations: AVE, average variance extracted; CFI, comparative fit index; CI, confidence interval; RMSEA, root mean square error of approximation; SRMR, standardized root mean square residual; TLI, Tucker–Lewis index.

DISCUSSION

The present study aimed to translate the original SE-12 by Axboe et al. (15) into German and assess its psychometric properties. The SE-12-G instrument proved to be a comprehensible and reliable tool and showed acceptable validity despite moderate fit indices.

Translation and assessment of comprehensibility as part of content validity

The translation process yielded a linguistically sound German version of the SE-12-G. Comprehensibility testing through cognitive interviews with healthcare professionals confirmed the clear understanding of the questionnaire, leading to no further adaptations. Inclusion of more participants with various backgrounds (e.g., various migration and cultural backgrounds) for testing the face-validity of the SE-12-G would provide information on the need of further adaptations.

Analyses of SE-12-G items, reliability and validity

The item analysis revealed generally high response rates and a low rate of missing values, indicating good participant engagement and the SE-12-G to be well-accepted by various HCPs.

Corrected item-total correlations are mostly above 0.66, indicating that most items measure the same underlying concept. Inter-item correlations are all above 0.30 indicating that all items are relevant and none should be deleted (40). Criteria for good item difficulties are met as mean item difficulty was 0.79 for the confidence-scale and for the importance-scale 0.91 and all values are above 50% highlighting the overall ease in responding (34). However, multiple ceiling effects were present. This is in line with previous studies applying the original SE-12 confidence-scale only (15, 18, 19), indicating that especially the importance-scale might be redundant. High ceiling effects may impede the identification of potential training effects in evaluations of communication skills trainings for HCPs. Nevertheless, the evaluation study by Johannsen et al. (23) found statistically significant improvements in the confidence and importance scores of the SE-12-G after training participation compared to the waitlist-control group at post-training assessment, supporting the SE-12-G sensitivity to detect change over time. As our sample comprises a large proportion of psychosocial HCPs and participation in a communication skills training was motivation for participation, further application of the SE-12-G in mixed samples of HCPs should be conducted to assess ceiling effects. Regarding the internal consistency, the SE-12-G shows excellent values and an overall good test-

retest reliability, which indicates that the questionnaire was consistent over the two measurement points (48, 49).

To our knowledge there are no measures that are related to the SE-12-G and could have been used to assess same or similar constructs. Therefore, we used latent constructs similar to Axboe and colleagues to explore the convergent validity of the SE-12-G. Our results show weak correlations between the confidence-scale and working experience (in general and with cancer patients), which is contrary to the findings of Axboe et al. (15). However, subsequent studies including other measurements, e.g., Attitudes towards Medical Communication (18), should be conducted to assess convergent validity. Regarding the discriminant validity, results indicate that HCPs' confidence (d=0.77) and importance (d=0.25) changed after a communication skills training. Known-group differences revealed various significant differences between different HCP subgroups in our sample in responses for specific items on the confidence-scale of the SE-12-G. Especially psychologists differed significantly and more often from physicians and nurses on the confidence-items. These findings highlight potential distinctions in perceptions among HCP groups regarding communication skills, which may be explained by different education, focus of care and time with the patients (e.g., psychologists and physicians).

Factor validity

We a priori hypothesized three models for the SE-12-G: a one-factor model replicating the original structure (M1), a two-factor model with continuous variables and residual covariance to account for methodological variance (M2), and an ordinal two-factor model to address non-normal data (M3a), which was then fitted further to check modified indicies and possible correlations (M3b). A confirmatory factor analysis confirmed the one-factorial structure of the original SE-12 with the confidence-scale only (M1), but fit indices were of no good fit. We tested additional a priori models, which slightly improved the model fit (especially M3b), but still could not find acceptable values. As

the convergent validity of all three models was low, with higher, but still inadequate AVE values for M3a and M3b for both factors (Table 8), values indicated that the latent constructs do not adequately capture the variance in its observed indicators (38). Yet, employing AVE for convergent validity relies on rules of thumb rather than statistical testing procedures, neglecting sampling errors and limiting the generalizability of conclusions to broader populations (50). Therefore, we prefer M3b (CFI=0.880, TLI=0.859, RMSEA=0.063 (95%CI)), but recommend to explore the CFA again with a.) a larger and more heterogenic sample (51) and b.) additional modifications (e.g., the exclusion of items with high ceiling effects).

Additionally, after further analysis for the SE-12-G and discussions with external experts on psychometric evaluations, methodology adjustments of the importance-scale might be necessary, to decrease its methodological dependence to the confidence-scale (i.e. “How important do you think it is to implement this in everyday working life?“ regarding the term “this”.) Still, as factor covariance lies within the cut off values of 0.30 and 0.70, results indicate that these two scales are distinct constructs despite the methodological dependence regarding the wording.

Limitations and strengths

This study has several limitations. First, divergent validity as part of psychometric parameters could not be analyzed due to the nature of this study being a secondary analysis. Second, the SE-12-G was applied to a selective sample of HCPs participating voluntarily in a communication skills training on child- and family-specific themes, resulting in sampling and volunteer bias. Further validation in different settings without participation in a communication skills training is needed to ensure generalizability. Third, some items exhibit close content-related associations, potentially exerting an influence in the variance within the factor analysis. A careful revision of the translated items might be indicated for these items. Lastly, the SE-12-G was included within a series of measures to evaluate

the effects of a communication skills training, taking approximately 30 minutes and therefore possibly influencing scoring of the SE-12-G.

A strength of this study is that we conducted an elaborated translation procedure, aligned with recommended survey translations. Additionally, we used cognitive interviews to explore face validity with various HCPs working in the field of communication and oncology. Further, we explored various models with an adequate sample to robustly perform factor analysis and various psychometric analyses.

CONCLUSION

Self-efficacy of HCPs in their communication skills should be assessed with valid and reliable measures. So far, an applicable and valid tool for all HCPs in German was lacking. With this study, we provide the first German measure for assessing self-efficacy in communication skills of HCPs including two subscales, the confidence and importance-scale. The German SE-12 (SE-12-G) is a brief measure with good acceptance and reliability. In our sample, psychometric properties were limited regarding the factor analysis and ceiling effects. This could be due to the sample composition (e.g., voluntary bias). In a next step, the SE-12-G should be further modified, and evaluated in a larger and more heterogenic sample of HCPs, that do not take part in an intervention.

DECLARATIONS

Ethics approval and consent to participate

The study is part of the study “Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study”, which was registered within the German Clinical Trial Register (DRKS-00015794) and approved by the Local Psychological Ethics Committee of the Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf, Germany (LPEK-001). The psychometric evaluation of the SE-12-G was a secondary analysis of data

gathered in the randomized controlled pilot-study. No administrative permission was required as all data were collected directly by the study team and no medical records were assessed. Written informed consent was obtained from all patients participating in the study. Study participation was voluntary.

Consent for publication

The article does not contain any individual's details and consent for publication is not applicable.

Availability of data and materials

The dataset collected and analyzed during this study is available from the corresponding author on reasonable request and after consultation of the Local Psychological Ethics Committee of the Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf.

Competing interests

The authors declare no competing interests.

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Authors' contributions

WF, LJ, LI and CB made substantial contributions to the design and preparation of the study. WF, LJ, LI and CB were involved in the translation and adaptation process. WF and LJ collected the data for psychometric evaluation. WF conducted the analysis. All authors contributed to the interpretation of results. WF drafted the manuscript and LJ, LI and CB were involved in critically revising the manuscript for important intellectual content. All authors gave final approval of the version to be published.

Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the authors used ChatGPT-3.5 in order to improve readability and language of the work. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

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REFERENCES

1. Moore PM, Rivera S, Bravo-Soto GA, Olivares C, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. Cochrane Database Syst Rev. 2018;7(7):Cd003751.
2. Kissane DW, Bylund CL, Banerjee SC, Bialer PA, Levin TT, Maloney EK, D'Agostino TA. Communication skills training for oncology professionals. J Clin Oncol. 2012;30(11):1242-7.
3. Stewart MA. Effective physician-patient communication and health outcomes: a review. Cmaj. 1995;152(9):1423-33.
4. Mauksch LB, Dugdale DC, Dodson S, Epstein R. Relationship, communication, and efficiency in the medical encounter: creating a clinical model from a literature review. Arch Intern Med. 2008;168(13):1387-95.
5. Street RL, Jr., Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. Patient Educ Couns. 2009;74(3):295-301.
6. Williams S, Weinman J, Dale J. Doctor-patient communication and patient satisfaction: a review. Fam Pract. 1998;15(5):480-92.
7. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J. The impact of patient-centered care on outcomes. J Fam Pract. 2000;49(9):796-804.
8. Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. Eur J Cancer. 1999;35(11):1592-7.
9. Harrington J, Noble LM, Newman SP. Improving patients' communication with doctors: a systematic review of intervention studies. Patient Educ Couns. 2004;52(1):7-16.
10. Uitterhoeve RJ, Bensing JM, Grol RP, Demulder PH, T VANA. The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature. Eur J Cancer Care (Engl). 2010;19(4):442-57.

11. Kerr D, Ostaszkiewicz J, Dunning T, Martin P. The effectiveness of training interventions on nurses' communication skills: A systematic review. Nurse Educ Today. 2020;89:104405.
12. Mata ÁNdS, de Azevedo KPM, Braga LP, de Medeiros GCBS, de Oliveira Segundo VH, Bezerra INM, et al. Training in communication skills for self-efficacy of health professionals: a systematic review. Human Resources for Health. 2021;19(1):30.
13. Berg MN, Ngune I, Schofield P, Grech L, Juraskova I, Strasser M, et al. Effectiveness of online communication skills training for cancer and palliative care health professionals: A systematic review. Psychooncology. 2021;30(9):1405-19.
14. Frerichs W, Geertz W, Johannsen LM, Inhestern L, Bergelt C. Child- and family-specific communication skills trainings for healthcare professionals caring for families with parental cancer: A systematic review. PLOS ONE. 2022;17(11):e0277225.
15. Axboe MK, Christensen KS, Kofoed PE, Ammentorp J. Development and validation of a self-efficacy questionnaire (SE-12) measuring the clinical communication skills of health care professionals. BMC Med Educ. 2016;16(1):272.
16. Efthymiou A, Kalaitzaki A, Rovithis M. Validation of the Self-Efficacy Questionnaire (SE-12-Gr) Assessing the Healthcare Professionals' Self-Reported Communication Skills with Older Healthcare Users in Greece. Health Communication.1-11.
17. Gil C-r, Sung KM. Validity and Reliability of the Korean Version of Self-Efficacy Questionnaire(KSE-12). Journal of Digital Convergence. 2020;18:337-45.
18. Escribano S, Juliá-Sanchis R, García-Sanjuán S, Congost-Maestre N, Cabañero-Martínez MJ. Psychometric properties of the Attitudes towards Medical Communication Scale in nursing students. PeerJ. 2021;9:e11034.
19. Wolderslund M, Kofoed PE, Ammentorp J. The effectiveness of a person-centred communication skills training programme for the health care professionals of a large hospital in Denmark. Patient Educ Couns. 2021;104(6):1423-30.
20. Hvidt EA, Ammentorp J, Søndergaard J, Timmermann C, Hansen DG, Hvidt NC. Developing and evaluating a course programme to enhance existential communication with cancer patients in general practice. Scandinavian journal of primary health care. 2018;36(2):142-51.
21. Desai S, Chen F, Boynton-Jarrett R. Clinician Satisfaction and Self-Efficacy With CenteringParenting Group Well-Child Care Model: A Pilot Study. J Prim Care Community Health. 2019;10:2150132719876739.
22. Kk A, At J, Lø P, Jd L, L L, S EN, et al. Effects of on-site Supportive Communication Training (On-site SCT) on doctor-patient communication in oncology: Study protocol of a randomized, controlled mixed-methods trial. BMC Med Educ. 2024;24(1):522.
23. Johannsen LM, Frerichs W, Philipp R, Inhestern L, Bergelt C. Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study. Psycho-Oncology. 2023;32(10):1567-77.
24. Inhestern L, Frerichs W, Johannsen LM, Bergelt C. Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot study. BMJ Open. 2019;9(10):e032778.
25. Harkness JA, Villar A, Edwards B. Translation, adaptation, and design. Survey methods in multinational, multiregional, and multicultural contexts. Wiley series in survey methodology. Hoboken, NJ, US: John Wiley & Sons, Inc.; 2010. p. 117-40.
26. Mohler P, Dorer B, De Jong J, Hu M. Translation. guidelines for best practice in cross-cultural surveys. Ann Arbor, MI: survey research center Institute for social research University of Michigan. 2016.
27. Harkness J, Pennell B-E, Schoua-Glusberg A. Survey Questionnaire Translation and Assessment. Methods for Testing and Evaluating Survey Questionnaires2004. p. 453-73.

28. Prüfer P, Rexroth M. Kognitive Interviews. 2005 [Available from: https://www.gesis.org/fileadmin/upload/forschung/publikationen/gesis_reihen/hohow/How_to15PP_MR.pdf.
29. Bannon W, Jr. Missing data within a quantitative research study: How to assess it, treat it, and why you should care. J Am Assoc Nurse Pract. 2015;27(4):230-2.
30. Flake JK, Pek J, Hehman E. Construct Validation in Social and Personality Research:Current Practice and Recommendations. Social Psychological and Personality Science. 2017;8(4):370-8.
31. Flora DB, Flake JK. The purpose and practice of exploratory and confirmatory factor analysis in psychological research: Decisions for scale development and validation. Canadian Journal of Behavioural Science / Revue canadienne des sciences du comportement. 2017;49(2):78-88.
32. Rogers P. Best Practices for Your Exploratory Factor Analysis: A Factor Tutorial. Journal of Contemporary Administration. 2021;26(6).
33. Rattray J, Jones MC. Essential elements of questionnaire design and development. J Clin Nurs. 2007;16(2):234-43.
34. Streiner DL, Norman GR, Cairney J. Health Measurement Scales: A practical guide to their development and use: Oxford University Press; 2014 01 Jan 2015.
35. Enders CK, Bandalos DL. The Relative Performance of Full Information Maximum Likelihood Estimation for Missing Data in Structural Equation Models. Structural Equation Modeling: A Multidisciplinary Journal. 2001;8(3):430-57.
36. Li C-H. Confirmatory factor analysis with ordinal data: Comparing robust maximum likelihood and diagonally weighted least squares. Behavior Research Methods. 2016;48(3):936-49.
37. Hu Lt, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. Structural Equation Modeling: A Multidisciplinary Journal. 1999;6(1):1-55.
38. Hair J BW, Babin B, Anderson RE . Multivariate data analysis. Upper Saddle River, NJ: Pearson Prentice Hall; 2009.
39. Ferketich S. Focus on psychometrics. Aspects of item analysis. Res Nurs Health. 1991;14(2):165-8.
40. Boateng GO, Neilands TB, Frongillo EA, Melgar-Quiñonez HR, Young SL. Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. Frontiers in Public Health. 2018;6.
41. McHorney CA, Tarlov AR. Individual-patient monitoring in clinical practice: are available health status surveys adequate? Qual Life Res. 1995;4(4):293-307.
42. Bannigan K, Watson R. Reliability and validity in a nutshell. J Clin Nurs. 2009;18(23):3237-43.
43. Hooper D, Coughlan, J., & Mullen, M. R. Structural Equation Modelling: Guidelines for Determining Model Fit. . The Electronic Journal of Business Research Methods. 2008;6:53-60.
44. Browne MW, Cudeck R. Single Sample Cross-Validation Indices for Covariance Structures. Multivariate Behav Res. 1989;24(4):445-55.
45. Fornell C, Larcker DF. Evaluating structural equation models with unobservable variables and measurement error. Journal of Marketing Research. 1981;18(1):39-50.
46. Cheung GW, Cooper-Thomas HD, Lau RS, Wang LC. Reporting reliability, convergent and discriminant validity with structural equation modeling: A review and best-practice recommendations. Asia Pacific Journal of Management. 2024;41(2):745-83.
47. Marsh HW, & Hau, K. T. . Confirmatory Factor Analysis: Strategies for Small Sample Sizes. Statistical Strategies for Small Sample Research. Statistical Strategies for Small Sample Research. 1999;1:251-84.
48. Portney LG, Watkins MP. Foundations of Clinical Research: Applications To Practice: Pearson/Prentice Hall; 2015.
49. Matheson GJ. We need to talk about reliability: making better use of test-retest studies for study design and interpretation. PeerJ. 2019;7:e6918.

50. Shiu E, Pervan SJ, Bove LL, Beatty SE. Reflections on discriminant validity: Reexamining the Bove et al. (2009) findings. Journal of Business Research. 2011;64(5):497-500.
51. Kyriazos TA. Applied Psychometrics: Sample Size and Sample Power Considerations in Factor Analysis (EFA, CFA) and SEM in General. Psychology. 2018;Vol.09No.08:25.

12. Statement on contributions to the publications

Publication 1. Inhestern L, **Frerichs W**, Johannsen LM, Bergelt C. (2019). *Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot-study.* BMJ Open, 9(10):e032778. doi: 10.1136/bmjopen-2019-032778.

WF made critical contributions to the design and preparation of the study. Furthermore, WF has written parts of the manuscript, contributed to and supported the revisions according to co-authors feedback.

Publication 2. **Frerichs W,** Geertz W, Johannsen LM, Inhestern L & Bergelt C. (2022). *Child- and family-specific communication skills trainings for healthcare professionals caring for families with parental cancer: A systematic review.* PLoS One, 17(11): e0277225. doi: 10.1371/journal.pone.0277225.

WF made substantial contributions to the study design and the preparation of the review. She developed the search strategy, extracted the data, analyzed and synthesized the data and interpreted the results. She wrote the first draft of the manuscript, revised it several times according to co-authors feedback and was responsible for the minor revision during the publication process.

Publication 3. Johannsen LM*, **Frerichs W*,** Philipp R, Inhestern L, Bergelt C. (2023) *Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study.* Psychooncology. 32(10):1567-1577. doi: 10.1002/pon.6207. * Shared authorship.

WF made substantial contributions to the study design and the preparation of the study. WF recruited participants, collected data, and analyzed the data as well together with LJ. Additionally, WF wrote parts of the first draft of the manuscript and was involved in the various revisions of the manuscript.

Publication 4. **Frerichs W**, Johannsen LM, Inhestern L & Bergelt C. (2025). *Providing care to cancer patients parenting minor children: a qualitative study on healthcare professionals' communication practice.* Patient Education and Counseling Jan 13;133:108666. doi: 10.1016/j.pec.2025.108666.

WF was partly responsible for the study design and the preparation of the study. Furthermore, WF recruited some participants and conducted some interviews. Additionally, she analyzed and interpreted all data together with a master student. Finally, WF wrote the first draft of the manuscript, revised it several

times according to co-authors feedback and was responsible for the minor revision during the publication process.

Publication 5. **Frerichs W**, Johannsen LM, Inhestern L & Bergelt C (submitted in 2024). *The German version of the self-efficacy questionnaire (SE-12-G) in a sample of healthcare professionals: Translation and psychometric properties*, 16 September 2024, PREPRINT (Version 1) available at Research Square [https://doi.org/10.21203/rs.3.rs-4836626/v1].

WF made substantial contributions to the study design and the preparation of the study. WF recruited participants, collected data, together with LJ. Additionally, she prepared and analyzed all data, wrote the first draft of the manuscript, revised it several times according to co-authors feedback and is responsible for the revision during the publication process.

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13. Curriculum Vitae

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Current Position:	Research Associate & PhD Research Student
Research Interests:	Patient-centered care, (Shared) decision-making in healthcare, Psycho-Oncology, Parenthood and cancer, Healthcare research, Healthcare communication, non-communicable diseases, health behavior change

Education:

PhD student 2019 – present	University of Hamburg, Germany – Faculty of Medicine, non-medical PhD Department of Medical Psychology, UKE Hamburg Supervisor: Prof. Dr. Corinna Bergelt Dissertation: *Communication skills of healthcare professionals when a parent has cancer – Development and evaluation of a communication training for healthcare professionals to support communication with cancer patients parenting minor children*
MSc Health Sciences 2012 – 2015	University of Applied Sciences Hamburg, Germany Department Health Sciences | Department of Medical Psychology, UKE Supervisor: Prof. Dr. Isabelle Scholl, Prof. Dr. Christine Adis Thesis: *Shared decision-making in oncology – A qualitative analysis of healthcare providers' views on current practice*
BSc Physical Therapy 2007 – 2011	Hanze University of Applied Sciences Groningen, the Netherlands Department of International Physical Therapy Supervisors: Prof. Dr. Elizabeth Dean, Prof. Dr. Hans van der Leur Thesis: *Can physical therapists counsel patients with lifestyle-related health conditions effectively? A systematic review and implications*
Exchange Programme 2010 – 2011	University of British Columbia, Canada Department of Physical Therapy, Supervisor: Prof. Dr. Elizabeth Dean

Research positions:

2021 – present	**Research Associate at Department of Medical Psychology** University Medical Center Hamburg-Eppendorf, Germany Research Group: Patient-Centered Care: Evaluation and Implementation, directed by Prof. Dr. Isabelle Scholl
2018 – 2021	**Research Associate at Department of Medical Psychology** University Medical Center Hamburg-Eppendorf, Germany Research Group: Psycho-Oncology, directed by Prof. Dr. Corinna Bergelt
2016 – 2018	**Research Associate at Department of Medical Psychology** University Medical Center Hamburg-Eppendorf, Germany Research Group: Clinical Healthcare Research Oncology, directed by Prof. Dr. Holger Schulz

Clinical and other work experience

2016 – present	**Sidepreneur & CEO** CALM Bootcamp | www.calmbootcamp.com • Personal Training with a focus on holistic movement therapy • Design and implementation of a female bootcamp class • Various health-promoting classes and courses for different companies (e.g., Beiersdorf AG, Zeit Verlag, Techniker Krankenkasse)
2014 – 2016	**Coordinator tesa sport club** Sportgemeinschaft Beiersdorf e.V. • Project management and coordination of the tesa sport clubs since 2015 inclugind leadership (> 10 employees) and budgeting • Development and implementation of health promotion courses of the Sportsgemeinschaft Beiersdorf e.V.
2011 – 2012	**Physical Therapist** • Unfallklinikum Boberg | 04/2012 — 07/2012 • Aqua Agil Praxis | 06/2011 — 09/2011 • ReGenesa Juist | 06/2011 — 09/2011

Teaching:

- University of Hamburg, Germany – Faculty of Medicine: shared decision-making, psycho-oncology, patient-centered communication skills, cancer and the family (since 2017)
- “Communicating with cancer patients parenting minor children” – a 3-hours interdisciplinary communication training for various healthcare professionals (face-to-face and web-based)
- Development of an e-learning (approximately 3-hours) for various healthcare professionals on the topic of ““Communicating with cancer patients parenting minor children”
- “Patient-centered communication in nursing practice” – 7-hour communication skills training for nursing professionals (face-to-face, since March 2023)

Supplementary Career Information

- Absence due to maternity leave and parenting periods in 01/2020-08/2020 and reduced hours due to parenting periods until 12/2021
- First generation academic

Research Awards:

- 2nd poster award 6th yCHCR early career scientists, June 2022; Hamburg- GER
- 3rd poster award of the 5th HAM-NET symposium, December 2021; Online
- 1st poster award of the 19th conference for psycho-oncology of the working group for psycho-oncology within the German Cancer Society (PSO), September 2021; Online
- "Jaco den Dekker Award 2011" scientific award for the best Bachelor thesis in physical therapy in the Netherlands 2010; Utrecht – NL
- „Crux Award 2011" award for the best Bachelor thesis in physical therapy at the Hanze University of Applied Sciences 2010; Groningen- NL

Professional Affiliations & Engagement

- International Association for Communication in Healthcare (EACH)- member within
  - tEACh – teaching subcommittee of EACH, active committee member, chair of the Asssessment group within tEACH (since 05/2024)
  - yEACH – early career subcommittee of EACH, active committee member
  - Special Interest Group – Healthcare communication in nursing, member
- German Society for Physiotherapy Science – member
- Center for Health Care Research (CHCR) – member (including the yCHCR for young professionals in healthcare research)
- Peer-reviewer for PLOS ONE, Supportive Care in Cancer, International Journal of Nursing Studies Advances, BMC Nursing, BMJ Open, BMC Cancer, BMC Medical Education, PEC

Publications (peer-reviewed):

2025 Møller JE, **Frerichs W**, Tsimtsiou Z, Schlömer J, Sator M, Rosenbaum M, Doherty E. *Advancing medical communication education internationally: tEACH collaborative initiatives*. Patient Educ Couns. 2025;134:108742. doi: 10.1016/j.pec.2025.108742.

Frerichs W, Inhestern L, Johannsen LM, Bergelt C. Providing care to cancer patients parenting minor children*: A qualitative study on healthcare professionals' communication practice.* Patient Educ Couns. 2025;133:108666. doi: 10.1016/j.pec.2025.108666.

Zisman-Ilani Y, **Frerichs W**, Silverstein S, Härter M. "Applying Shared Decision Making to Address Biopsychosocial Factors in Psychosomatic Conditions" in Elwyn G, Joseph-Williams and Edwards A (eds.), *Shared Decision-Making in Healthcare*, 4th Edition. Oxford, Oxford University Press, 2025, in press.

2024 Gilligan C, Bujnowska-Fedak M, Essers G**, Frerichs W**, Brinke D, Junod Perron N, Kiessling C, Pype P, Tsimtsiou Z, Van Nuland M, Wilkinson T, Rosenbaum M. *Assessment of communication skills in health professions education; Ottawa 2024 consensus statement.* MED TEACH. 2024;46(12):1593-1606.

Frerichs W, Inhestern L, Johannsen LM, Bergelt C. *The German version of the self-efficacy questionnaire (SE-12-G) in a sample of healthcare professionals: Translation and psychometric properties*, under Peer Review at BMC Med Educ. 16 September 2024, preprint (Version 1) available at Research Square https://doi.org/10.21203/rs.3.rs-4836626/v1.

Mielke K, Frerichs W, Cöllen K, Lindig A, Härter M, Scholl I. *Development of a patient-centered communication skills training: A qualitative exploration of nurse managers' perspectives*, accepted BMC NURS; preprint available at https://doi.org/10.21203/rs.3.rs-5287510/v1.

Mielke K, Frerichs W, Cöllen K, Lindig A, Härter M, Scholl I. *Perspective on patient-centered communication: a focus group study investigating the experiences and needs of nursing professionals*. BMC NURS. 2024;23(1):822.

Lindig A, Mielke K, Frerichs W, Cöllen K, Kriston L, Härter M, Scholl I. *Evaluation of a patient-centered communication skills training for nurses (KOMPAT): study protocol of a randomized controlled trial*. BMC NURS. 2024;23(1):2.

Thomas M, Mielke K, Lindig A, Frerichs W, Scholl I. *Patient:innenzentrierte Kommunikation in Aufklärungsgesprächen – Herausforderungen und Lösungsansätze*. ONKOLOGIE-GER. 2024;30:214-221.

2023 Geertz, W, Frerichs W, Inhestern L, Bergelt C. *Supportive and psychosocial peer-group interventions for children and adolescents of parents with cancer: A systematic review.* Patient Educ and Couns 8;114:107844. doi: 10.1016/j.pec.2023.107844.
Lindig A, Frerichs W, Hahlweg P, Scholl I. *Shared decision-making in Oncology.* Best Practice Onkologie.

Hahlweg P, Lindig A, Frerichs W, Zill J, Hanken H, Müller V, Peters M, Scholl I. *Major influencing factors on routine implementation of shared decision-making in cancer care: qualitative process evaluation of a stepped-wedge cluster randomized trial.* BMC HEALTH SERV RES. 2023;23(1):840.

Johannsen L, Frerichs W, Inhestern L, Bergelt C. *Exploring the perspectives of cancer patients parenting minor children about their care experience: A qualitative study on family-centered cancer care.* Patient Educ and Couns 117(12):107989. doi:10.1016/j.pec.2023.107989.

Lindig A, Mielke K, Frerichs W, Cöllen K, Kriston L, Härter M, Scholl I. *Evaluation of a patient-centered communication skills training for nurses (KOMPAT): study protocol of a randomized controlled trial.* (in revision BMC Nursing).

Johannsen L*, Frerichs W*, Phillip R, Inhestern L, Bergelt C. *Effectiveness of a training program for healthcare professionals on parental cancer: Results of a randomized controlled pilot-study.* PSYCHO-ONCOLOGY 32(10):1567-1577. *Shared first authorship.

2022 Frerichs W, Geertz, W, Johannsen L, Inhestern L, Bergelt C. *Child- and family-specific communication skills trainings for healthcare professionals caring for families with parental cancer: A systematic review.* PLOS ONE 17(11): e0277225.

Johannsen LM, Brandt M, Frerichs W, Inhestern L, Bergelt C. *The impact of cancer on the mental health of patients parenting minor children: A systematic review of the quantitative evidence.* PSYCHO-ONCOLOGY 31(6): 869-878.

2021 Scholl I, Hahlweg P, Lindig A, Frerichs W, Zill J, Cords H, Bokemeyer C, Coym A, Schmalfeldt B, Smeets R, Vollkommer T, Witzel I, Härter M, Kriston L. *Evaluation of a program for routine implementation of shared decision-making in cancer care: results of a stepped wedge cluster randomized trial.* IMPLEMENT SCI.16(1).

2020 Lindig A, Hahlweg P, **Frerichs W,** Topf C, Reemts M, Scholl I. *Adaptation and qualitative evaluation of Ask 3 Questions - a simple and generic intervention to foster patient empowerment.* HEALTH EXPECT 23(5): 1310-1325.

Johannsen LM, **Frerichs W**, Inhestern L, Bergelt C. *Assessing Competencies of Healthcare Professionals Caring for Parents With Cancer: The Development of an Innovative Assessment Tool.* PSYCHO-ONCOLOGY 29(10): 1670-1677.

2019 Inhestern L, **Frerichs W**, Johannsen LM, Bergelt C. *Process-evaluation and outcome-evaluation of a training programme for healthcare professionals in oncology to enhance their competencies in caring for patients with minor children: a study protocol for a randomised controlled pilot study.* BMJ OPEN. 9(10): e032778.

Christalle E, Zill JM, **Frerichs W**, Härter M, Nestoriuc Y, Dirmaier J, Scholl I. *Assessment of patient information needs: A systematic review of measures.* PLOS ONE 14(1): e0209165.

2018 Schulz H, Bleich C, Dabs M, **Frerichs W**, Sautier L, Bokemeyer C, Koch-Gromus U, Härter M. *Psychoonkologische Versorgung in Deutschland: Bundesweite Bestandsaufnahme und Analyse: Wissenschaftliches Gutachten im Auftrag des Bundesministeriums für Gesundheit.*

2016 **Frerichs W,** Hahlweg P, Müller E, Adis C, Scholl I. *Shared decision-making in oncology - A qualitative analysis of healthcare providers' views on current practice.* PLOS ONE 11(2): e0149789.

2012 **Frerichs W,** Kaltenbacher E, van de Leur JP, Dean E. *Can physical therapists counsel patients with lifestyle-related health conditions effectively? A systematic review and implications*. Physiother Theory Pract. 28(8): 571-87.

Conference Presentations (selection):

- *Challenges and opportunities of patient-centered communication. Frerichs W* 1st Latin American Congress on person-centered care, Santiago de Chile (Chile) 2024 – Key Note Presentation.
- *Development of standardized patient assessment tool for patient-centered communication in nursing. Frerichs W, et al.* International Conference on Communication in Healthcare (ICCH), Zaragossa (Spain) 2024 – Oral Presentation.
- *Outcome differences between health professionals participating in a communication intervention when a parent has cancer.* Frerichs W, et al. International Conference on Communication in Healthcare (ICCH), Glasgow (Scotland) 2022 – Oral Presentation.
- *Development and evaluation of a patient-centered communication skills training for nurses*. Frerichs W, et al. International Conference on Communication in Healthcare (ICCH), Glasgow (Scotland) 2022 – Oral Presentation.
- *COVID-19 adaptations - communication skills training for professionals treating parents with cancer.* Frerichs W, et al. International Conference on Communication in Healthcare (ICCH), 2021 Online – Oral Presentation.
- *Healthcare professionals participating in a communication skills training to enhance their competencies in caring for cancer patients with minor children: Current communication and attitudes towards family-related aspects*. Frerichs W, et al. 22nd World Congress of Psycho-Oncology (IPOS), 2021 Online – Oral Presentation.

- *Satisfaction and applicability of communication training for healthcare providers on parental cancer, adapted to COVID-19 contact restrictions.* Frerichs W, et al. DGMP/DGMS Congress 2021, Online – Oral Presentation.
- *Exploring healthcare professionals' communication with cancer patients parenting minor children: A qualitative study of identifying barriers, experiences and attitudes.* Frerichs W, et al. 21st World Congress of Psycho-Oncology (IPOS), Banff (Canada), 2019 – Oral Presentation.

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16. Eidesstattliche Versicherung

Ich versichere ausdrücklich, dass ich die Arbeit selbständig und ohne fremde Hilfe, insbesondere ohne entgeltliche Hilfe von Vermittlungs- und Beratungsdiensten, verfasst, andere als die von mir angegebenen Quellen und Hilfsmittel nicht benutzt und die aus den benutzten Werken wörtlich oder inhaltlich entnommenen Stellen einzeln nach Ausgabe (Auflage und Jahr des Erscheinens), Band und Seite des benutzten Werkes kenntlich gemacht habe. Das gilt insbesondere auch für alle Informationen aus Internetquellen. Soweit beim Verfassen der Dissertation KI-basierte Tools („Chatbots“) verwendet wurden, versichere ich ausdrücklich, den daraus generierten Anteil deutlich kenntlich gemacht zu haben. Die „Stellungnahme des Präsidiums der Deutschen Forschungsgemeinschaft (DFG) zum Einfluss generativer Modelle für die Text- und Bilderstellung auf die Wissenschaften und das Förderhandeln der DFG“ aus September 2023 wurde dabei beachtet. Ferner versichere ich, dass ich die Dissertation bisher nicht einem Fachvertreter an einer anderen Hochschule zur Überprüfung vorgelegt oder mich anderweitig um Zulassung zur Promotion beworben habe. Ich erkläre mich damit einverstanden, dass meine Dissertation vom Dekanat der Medizinischen Fakultät mit einer gängigen Software zur Erkennung von Plagiaten überprüft werden kann.

Hamburg, _____ 2025

Wiebke Frerichs