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Study protocol OKRA: orientation compass for the preparing, delivering and following up on breaking bad news conversations in paediatric oncology

Theresia Krieger ,[1] Kerstin Dittmer,[2] David Reinert,[2] Marc Hömberg ,[3] Andrea Tepe,[4] Isabel Hamm,[5] Frank Vitinius[5,6]

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For numbered affiliations see end of article.

Correspondence to
Dr Theresia Krieger; theresia.krieger@uk-koeln.de

ABSTRACT

Introduction In paediatric oncology, 'breaking bad news'—BBN—like cancer diagnosis is perceived as particularly challenging. Enabling a trialogue between children with their relatives and health professionals requires profound communication skills. Lacking the skills, experience or adequate support tools might result in negative consequences for both paediatric oncologists as BBN transmitters and BBN receivers as children with cancer and their relatives.

In contrast to oncology for adults, multiperspective studies that explore BBN experience and specific support needs are rare, especially in Germany. Systematically developed and practically piloted support instruments, which address the specific needs of paediatric oncology, are missing.

Objective To systematically design and mature in practice an orientation compass for preparing, delivering and following up on BBN conversations in paediatric oncology—so-called Orientierungskompass zur Übermittlung schwerwiegender Nachrichten in der Kinderonkologie (OKRA).

Methods and analysis OKRA is based on a QUAL-quant mixed study design, comprising two phases. Four groups will contribute (1) experts through personal experience (representatives for children receiving BBN and their parents), (2) medical care providers and representatives of national medical societies, (3) ambulant psychosocial/psychological support providers and (4) researchers. In phase 1, multiperspective knowledge is generated through a participatory group Delphi that involves in-depth interviews, focus group discussions and questionnaires. This process culminates in formulating theses for a high-quality BBN process (output phase 1). In phase 2, based on the theses, a pilot orientation compass is designed. Through iterative cycles with the participatory action research method, this instrument will be piloted in three paediatric oncological settings and consequently optimised.

Ethics and dissemination OKRA was approved on 19 September 2023 by the ethics committee of the Medical Faculty of the University of Cologne (No. 23-1187). After project completion, the OKRA compass will be distributed to multidisciplinary paediatric oncology teams throughout Germany.

Trial registration number DRKS00031691.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Although breaking bad news (BBN) in paediatric oncology is considered challenging, little is known about the specific needs of the transmitters or receivers during the trialogue, and age-specific protocols are lacking.

WHAT THIS STUDY ADDS

⇒ A multiperspective understanding of the perceived needs and wishes for BBN will be generated. Based on these findings, an 'orientation compass' for BBN will be designed and consecutively matured in practical application. This final product will be accessible to all paediatric oncology departments in Germany.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The compass, which was designed through a participative approach, may be considered a needs-driven instrument, which assists health professionals to prepare, guide and follow-up BBN processes in a systematic manner. It may improve the BBN processes' quality and help children and parents to better cope with the situation. Particularly in the training of healthcare professionals, the compass may sensitise to the BBN implications, provide guidance and reduce emotional stress.

INTRODUCTION

In Germany, around 2200 children and adolescents (under the age of 18) are newly diagnosed with cancer every year.[1] The cure rates for paediatric cancer have improved significantly in recent decades so that the average 15-year survival rate in Germany is 82%. Nevertheless, there are still around 410 deaths per year within 15 years of cancer diagnosis.[2]

Breaking bad news (BBN) refers to those conversations that may change the patient's view of their future in a drastic, negative way.[3] BBN comprises different types of information, for example, the diagnosis of cancer, the progression or recurrence of the disease.[4]

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BBN plays a central role in the routine of clinical oncology.[5] Meanwhile, due to its complex requirements, BBN is considered a major communicative challenge.[4 6] The quality of the BBN conversation is considered crucial, which influences the patient's course of treatment, including adherence to treatment or the ability to deal with challenges in therapy and cancer-related self-efficacy to cope with emotional distress.[7 8]

In adult oncology, various communication trainings[9 10] and 'protocols for BBN' (eg, SPIKES, ABCDE; BREAKS) exist.[5 11 12] The transferability of these protocols to the paediatric setting remains unsearched.

Breaking and receiving bad news in paediatric oncology

In contrast to adult oncology for adults, for paediatric oncology, a comprehensive understanding of experiences and the needs from multiple perspectives (eg, from the perspective of the BBN transmitter and receiver) are missing.[13 14] In this setting, a trialogue communication between the multidisciplinary paediatric oncology team, patients and their parents is obligatory.[6 14 15] Therefore, BBN transmitters often perceive this task as even more stressful than in adult oncology.[6 16]

Nevertheless, international publications on BBN transmitters' experiences, needs and perceived bottlenecks related to BBN in paediatric oncology are rare and context-specific knowledge from Germany is missing. Paediatric oncology studies from Canada and Sweden indicate that many BBN transmitters (eg, physicians, psychologists and nurses) perceive it as 'a challenge' and often feel 'uncomfortable', 'vulnerable' or 'insufficiently prepared'.[16 17] Paediatricians in outpatient care declare a lack of knowledge, experience and/or communication skills to 'successfully' and 'appropriately' manage the BBN trialogue.[18]

Cancer in children affects the entire family system.[14 15] The BBN process might have a negative impact on its receivers' treatment adherence, quality of life, symptom reduction or emotional health.[19] However, only a few studies explored the BBN experiences of children and their families, whether in an ambulatory or inpatient setting. Adolescents and young adults of a cancer self-help group designate BBN as a 'biographical turning point', which may trigger a range of emotional complaints (eg, depression) that was even aggravated by social isolation caused by the treatment trajectory.[20 21] Likewise, little is known about parents of children with cancer BBN experiences.[16] Some parents describe strong emotional outbursts and even physical breakdowns during or after the counselling session.[22]

BBN support needs and guidance in paediatric oncology

Adolescents with cancer emphasised that providing understandable information, establishing a stable and trustful relationship and applying the principles of participatory (ie, shared) decision-making are important for BBN.[20]

A systematic, paediatric-specific and evidence-based guidance is missing. The extent to which support protocols from oncology (eg, SPIKES[5] might be transferred to paediatric oncology (doctor/child as patient/parent trialogue) remains insufficiently investigated. Family-centred communication, which includes complex family dynamics, is considered promising for BBN in paediatric oncology.[16 23] For this type of communication, we consider the BUSTER protocol,[24] with its systemic approach, as particularly suitable for the paediatric context. Finally, it remains unclear to what extent the BBN protocols for adults are applied in Germany in the paediatric setting and what experiences have been made with them. Given the specific challenges of BBN processes in paediatric oncology, combined with the lack of existing protocols for the given context, the necessity for the development of a context-specific, needs-driven and practice-based instrument becomes evident.

Objective

Within the research project OKRA (German acronym for Orientierungskompass zur Übermittlung schwerwiegender Nachrichten in der Kinderonkologie), a tailored support instrument—the so-called 'orientation compass' for health professionals in paediatric oncology should be systematically designed and matured in practice.

This compass aims to (1) comprehensively prepare professionals for the BBN trialogue (eg, with children with cancer and their parents), (2) guide them through the BBN conversation itself and (3) offer follow-up impulses for both BBN transmitters and receivers.

METHODS AND ANALYSIS

Research team

The research team consists of five professionals with experiences in psychology, psychosomatic and general medicine, healthcare development, nursing sciences and public health. They are affiliated with the University of Cologne and Robert-Bosch Hospital Stuttgart; none of them is or has been employed by any of the organisations involved in the study.

Study design

OKRA has an explorative and participatory character. It follows a QUAL-quant mixed-methods research approach, which is suitable for considering the various perspectives on the complex issue of BBN.[25 26] QUAL indicates that different qualitative methods will be applied in both phases (eg, interviews or focus group discussions), whereas the quant indicates that only a small part of the study includes quantitative measures (phase 1).[27] Emphasises are given to qualitative methods and the Consolidated criteria for Reporting Qualitative research criteria are applied to this study protocol.[25 28]

By applying the participatory approach, participants are constantly empowered to incorporate their perspective, which may lead to a contextualised, needs-driven

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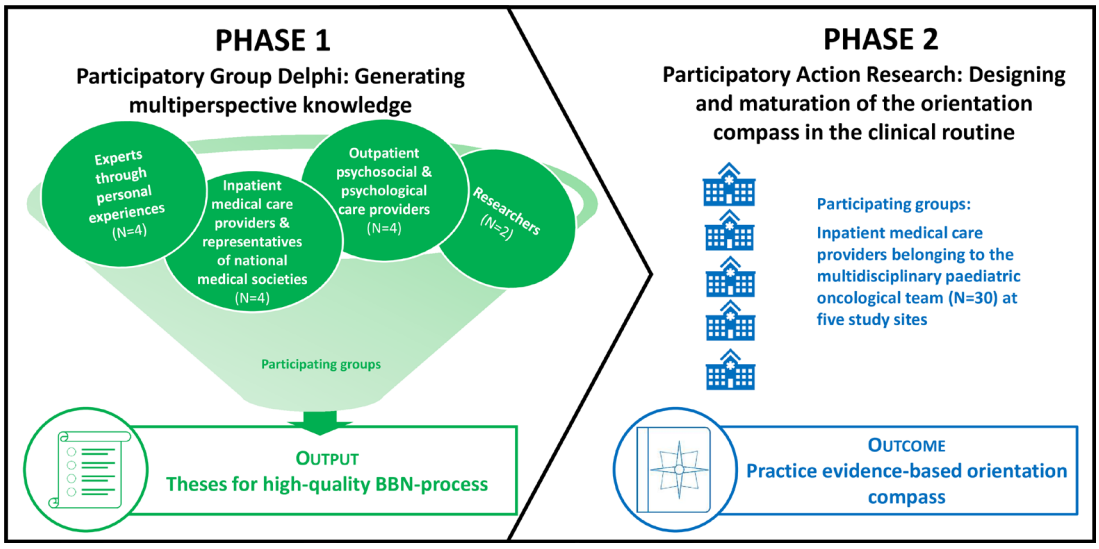


Figure 1 QUAL-quant mixed-methods study design of OKRA with its two phases. OKRA, Orientierungskompass zur Übermittlung schwerwiegender Nachrichten in der Kinderonkologie.

and comprehensible outcome—the OKRA compass. Figure 1 illustrates the OKRA design, which consists of two consecutive phases.

The corresponding data collection methods, participating groups, outputs and study outcomes are highlighted in the following text.

Phase 1: participatory group Delphi: generating multiperspective knowledge

OKRA starts with a participatory group Delphi (PGD) (figure 1, left side).[29 30] PGD is a discursive method with several consensus rounds that are considered as appropriate when aiming to design knowledge-based guidelines or checklists[31] while considering multiple perspectives (eg, those receiving and transmitting BBN).[29 30] PGDs permit an open, equal and constructive dialogue between the different participants and lead to a broad generation of knowledge. Participants have the opportunity to reconsider and revise their statements or assessments at any time.[29]

The OKRA PGD consists of six consecutive rounds, as described in table 1. When calculating the number of organisations needed to fully understand the BBN issues in paediatric oncology, we understood that there are basically four groups involved in the BBN issue. They are 14 dedicated representatives of the cooperation and belong to four expert groups: (1) 'experts through personal experience' (representatives of children receiving BBN and their parents), (2) medical care providers and representatives of national medical societies, (3) outpatient psychosocial support providers and (4) researchers (figure 1, left side). Four experts from each group participated, except for the group of external researchers, which has only two. The number of members in each group should be balanced and large enough to outline

Table 1 Description of the OKRA participatory group Delphi (PGD) rounds

PGD round	Data collection method	Participants	Aim
1	Individual, semistructured explorative **interviews**	14 experts*	Gather a multiperspective understanding of needs concerning BBN preparation, transmission and follow-up in the paediatric settings
2	First **focus group discussion**	14 experts*	Formulate preliminary theses for adequate delivery of BBN in the paediatric oncology
3	First **survey** with open text options	56 experts†	Evaluate and optimise preliminary theses
4	Second **focus group discussion**	14 experts*	Formulate final theses based on the survey results by consensus
5	Second **survey**	56 experts†	Prioritise final theses
6	Third **focus group discussion** (consenting workshop)	14 experts*	Agree on final theses for a high-quality BBN process as a basis for the orientation compass (output)

*Constant group composition containing (1) experts through personal experience, (2) medical care providers and representatives of national medical societies, (3) outpatient psychosocial support providers and (4) researchers.
†Experts from PGD round 1 and three other persons from their organisation.
BBN, breaking bad news; OKRA, Orientierungskompass zur Übermittlung schwerwiegender Nachrichten in der Kinderonkologie.

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the perspective. We decided that four originators would be appropriate for groups 1–3. In group 4 (researchers), only two organisations are involved because the OKRA research team is also part of this group and it includes two organisational perspectives. In the end, 14 external organisations contributed as coresearchers. It is also important to recognise that the participants do not speak for themselves but present the perspective of their organisation. Participants are located throughout Germany and are continuously engaged.

In order to augment the scope, for the 2 written surveys, these 14 participants may select three other persons from their own organisation with expertise in the subject matter, so that a maximum of 56 participants can be expected in the PGD, thereby meeting the recommended group size.[30]

In round 1, items will be generated for each subject through one individual expert interview with one person from each organisation (N=14) (table 1). Theses will then be generated and prioritised based on this knowledge through focus group discussions (rounds 2 and 4) with the same participants of round 1. In round 3, a survey with open text option and in round 5, a survey with a 5-point Likert scale will be offered.

This process results in the joint formulation of final theses (output phase 1) which serve as the base for the development of the pilot orientation compass (phase 2).

Phase 2: participatory action research: designing and maturing of the orientation compass in the clinical routine

Second, the pilot orientation compass is designed and refined in clinical reality using the participatory action research (PAR) method[32 33] (figure 1, right side). PAR is used to improve practice (eg, BBN transfer) through the simultaneous process of action and research and the non-linear, iterative process of learning by doing.[34] PAR combines collective reasoning with evidence-based learning that is embedded in active collaboration (eg, BBN transmitters and researchers) and includes the following three elements: (1) participation (eg, active engagement and codesigning of those involved in the process, (2) action and (3) research.[35]

The compass will be matured in five different federal states through the participation of multidisciplinary team members (eg, physicians, nurses and psychosocial support) in paediatric oncology. During this phase, participants from phase 1 will be invited to participate intentionally. A maximum of 30 BBN transmitters, belonging to the multidisciplinary paediatric oncology team from five study sites, are expected to participate (figure 1, right side). Based on PAR experiences, 2–3 maturation loops are appropriate.[32]

Based on the outputs of phase 1 (final theses for a high-quality BBN process), the research team started to design a pilot orientation compass for BBN in paediatric oncology (figure 1, right side). Its maturation is achieved through iterative PAR learning and a total of three optimisation cycles (figure 2) in practice within three paediatric oncology clinics. Each of our PAR cycles includes four steps: plan, act, observe and reflect.[36] Table 2 specifics this maturation process.

Inclusion criteria and participants

The study will include only adult participants with an extensive content-specific expertise. The first group, known as ‘experts through personal experience’, also represents the perspective of children receiving BBN. However, these individuals are part of a self-help group organisation comprised adults who were affected by cancer during childhood. Further inclusion criteria are (1) ability to actively participate in online data collection, (2) unrestricted or adequately corrected vision and hearing (3) and very good German language skills.

Data collection and analysis

For reasons of feasibility (geographical distribution of participants), all data collection during the PGD will be conducted onlineBox 1. Participants must have

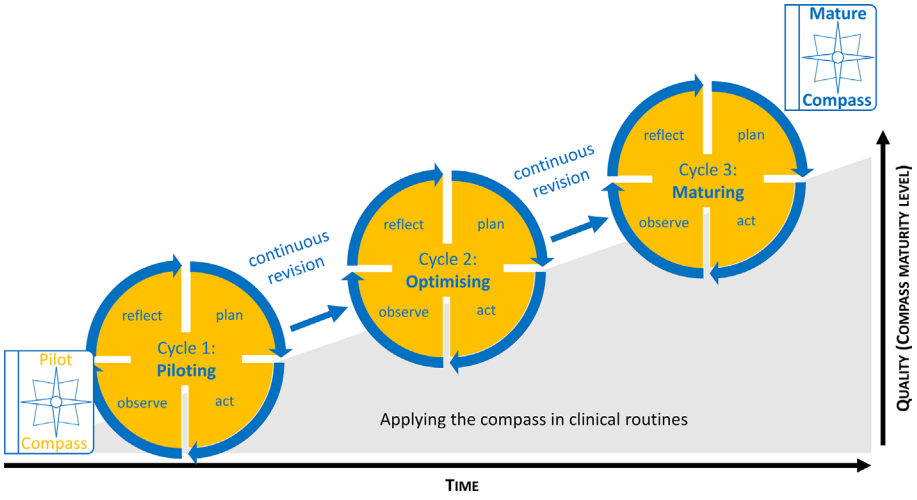


Figure 2 Participatory action research cycles in OKRA. OKRA, Orientierungskompass zur Übermittlung schwerwiegender Nachrichten in der Kinderonkologie.

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Table 2 Description of the maturing process of the OKRA orientation compass in practice via participatory action research (PAR)

PAR steps with activities and participants			
STEP 1—Plan	**STEP 2—Act**	**STEP 3—Observe**	**STEP 4—Reflect**
Research team members design (first cycle) or optimise the compass (eg, insert new text passages of figures).	BBN transmitters (eg, paediatric oncologists) at three study sites apply the compass in their clinical care practice for BBN preparation, transmission and follow-up.	BBN transmitters identify optimisation potential and communicate it to the research team in digital documents. To assess the quality of the compass, a short questionnaire is handed out to the users.	Research team members discuss optimisation feedback from the three study sites with the BBN transmitters (eg, focus groups) with regard to the degree of completion of the compass, as well as its perceived effectivity on both BBN transmitters and receivers.

BBN, breaking bad news; OKRA, Orientierungskompass zur Übermittlung schwerwiegender Nachrichten in der Kinderonkologie.

a computer with a good internet connection and a camera to make the study technically feasible. Interactive whiteboards will be used for focus group discussions. According to the German General Data Protection Regulation (GDPR), a protected ZOOM access and LIME Survey version, offered by the University of Cologne, is used for data collection. Participant's metadata (eg, age, setting, profession and specific skills) are gathered via a short questionnaire and analysed descriptively via SPSS.

Phase 1: PGD

Semistructured interview guidelines (see online supplemental appendix 1) are developed for qualitative data collection.[37] The instrument will be piloted by a professional of the paediatric oncology team of the University Hospital Cologne and a member of the Foundation for Children with Cancer with affiliated Parent-House ('Elternhaus e.V.', Cologne). Subsequently, the piloting individuals are not included in the study. During all qualitative data collection, audio recordings are conducted and supplemented by short written memos of the researchers. During the focus group discussions, speaker turnover is documented. All audio recordings are then transcribed and pseudonymised. The transcripts are coded independently by two researchers (inter-rater reliability), using the software MAXQDA (V.24).[38] The method of thematic analysis is applied, including six steps: (1) familiarisation with the data material, (2) development of initial codes, (3) search for topics, (4) examination of topics, (5) specification and naming of topics and (6) preparation of the analysis results.[39]

The items for the two Delphi questionnaires (quantitative) in rounds 3 and 5 are identified through the previous individual interviews and focus group discussions. The results are converted into theses for the OKRA Delphi questionnaire and presented to the respondents via LIME Survey for standardised assessment. The surveys are carried out pseudonymously by assigning codes so that the code can also be assigned to the respective participant in the second survey. Participants are asked to appraise each thesis from different perspectives (eg, time of realisation, obstacles to realisation or importance of the thesis).

During round 3, survey participants were given the option to include or exclude the theses that were formulated in the previous sessions (open text option). In addition, participants can make additions by using open-ended questions with a free text option.[30] If a thesis reaches a consensus of over 95% in round 3 (survey), it will be considered accepted. Theses rated between 80% and 95% will require optimisation while those that receive less than 80% will be withdrawn.

During round 5, a unidimensional 5-point Likert scale questionnaire will be used to weigh the theses. The scale ranges from 'very important' to 'not important at all'.[31] The statistical analysis of the OKRA surveys is descriptive, with means and SDs calculated from the answers to the questionnaire. The final theses will be presented as follows: 'very important' with a percentage greater than 90% (indicated by ↑↑), 'important' with a percentage between 70% and 90% (indicated by ↑) and 'wishful' with a percentage less than 70% (indicated by ↔). The statistical analysis of the OKRA surveys is descriptive. Means and SDs are calculated from the answers to the questionnaires.

Phase 2: PAR

In phase 2, the respective maturity level of the pilot orientation compass is assessed through oral (via focus group discussions) or written reflection loops (eg, via text comment function). This is accompanied by an user-friendly optimisation tool (UPIM check) with a traffic light system that considers 'green' items as mature whereas 'yellow' and 'red' require optimisation impulses.[40] This instrument offers a systematic examination and maturation of the compass regarding four items: (1) content correctness and validity, (2) content readability, (3) structural readability and (4) graphical readability.

Patient and public involvement

In OKRA, children's and parents' self-help as well as ambulant support organisations were selected to ensure a high level of public involvement (figure 1, left side). Due to the chosen methodology (PGD and PAR), paediatric patients themselves are not involved.

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Box 1 Strengths and limitations of this study

Given the paucity of evidence, the mixed-methods approach (participatory group Delphi (PGD) and participatory action research) permits gaining a comprehensive understanding, as well as developing, piloting and maturing a needs-driven breaking bad news (BBN) support instrument for paediatric oncology.

Applying a participatory approach continuously, helps to adequately incorporate the needs of the BBN transmitters (health professionals) and receivers (paediatric cancer patients and their parents) in the instrument, which improves its quality, understandability and acceptance (compass).

By enabling a collaboration between a multidisciplinary research team, content-specific experts and healthcare providers, it is ensured, that a wide range of perspectives is taken into consideration.

The PGD methodology represents a method to achieve expert consensus via comprehensive synthesis of essential factors in a specific context. Transnational transferability needs to be tested. Replication by other researchers is possible when aiming to explore needs-tailored and design-tailored interventions in the clinical setting.

Collecting data online has both limitations and advantages. It is considered the gold standard to conduct focus groups face to face. However, even before the Corona crisis, studies looking at the differences between online and face to face did not find significant differences.[41] Other research highlights the superficiality of the responses, which lack contextual details produced in the online environment and a question-answer to the detriment and not a spontaneous conversational between participants.[42] Researchers should be aware that technology and digital literacy, recruitment, group size, level of prior knowledge, the role of the interviewer, the participants' media environment and data management may affect the quality of online data collection. However, the availability of the experts and geographical distances can be overcome by using online formats. It would not have been reasonable for most experts to attend four face-to-face meetings in the given time planned for that activity. They offer an opportunity to reduce the amount of travel required by researchers and participants to and from focus group locations and can be time-saving and cost-effective.[43] When online focus groups provide a practical and convenient communication space for both participants and researchers, they also facilitate the inclusion of geographically dispersed participants and provide an opportunity to study hard-to-reach populations.[44] As all participants had the technical skills and experience of online meetings, and the research team had been trained in the specific challenges of online data collection, it was decided to conduct the interviews and focus groups online. In summary, the online approach has strengths and limitations.

All participants of the BBN trialogue (transmitters and receivers) are engaged in order to design a comprehensive, appropriate and accepted support instrument for the German paediatric oncology. OKRA-participants are constantly empowered to participate in cocreative learning and codesigning processes with the research team.

DISSEMINATION

Our study results will be published in a peer-reviewed journal based on recognised reporting statements and in grey literature (eg, self-help journals). The criteria of the International Committee of Medical Journal Editors are binding for the authors.

Author affiliations
[1]Medical Psychology | Neuropsychology and Gender Studies & Centre for Neuropsychological Diagnostics and Intervention (CeNDI), University of Cologne and Faculty of Medicine and University Hospital Cologne, Cologne, Germany
[2]Faculty of Medicine, Department of Medical Psychology, Neuropsychology and Gender Studies & Centre for Neuropsychological Diagnostics and Intervention (CeNDI), University of Cologne and University Hospital Cologne, Cologne, Germany
[3]Department of Paediatric Oncology and Haematology, Children's Hospital, University of Cologne, Cologne, Germany
[4]Foundation for Children with Cancer with Affiliated Parent-House, Cologne, Germany
[5]Department of Psychosomatics and Psychotherapy, University of Cologne and Faculty of Medicine, Cologne, Germany
[6]Department of Psychosomatic Medicine, Robert Bosch Hospital, Stuttgart, Germany

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Contributors TK: applicant of the study, conceptualisation, investigation, methodology, validation, visualisation, writing—original draft, project management. KD: investigation, validation, visualisation, resources, writing—review and editing. DR: investigation, validation, resources, writing—review and editing. MH: investigation, resources, writing—review and editing. AT: investigation, validation, resources, writing—review and editing. IH: supervision, validation, resources, writing—review and editing. FV: applicant of the study, conceptualisation, investigation, methodology, validation, reviewing and editing.

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Competing interests None to declare.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval OKRA has been approved by the ethics committee of the Medical Faculty of the University of Cologne (No. 23-1187). Compliance with the General Data Protection Regulation (GDPR) and the North Rhine-Westphalia State Data Protection Act is fully guaranteed.

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ORCID iDs
Theresia Krieger http://orcid.org/0000-0002-7414-7318
Marc Hömberg http://orcid.org/0000-0002-6928-7973

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