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Developing multi-perspective practice-based evidence theses for breaking bad news in the German pediatric oncology: A participatory group Delphi study

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ABSTRACT

Objectives: The study aimed to (1) gain a comprehensive, multi-perspective understanding of the preparation, transmission and follow-up of Breaking Bad News (BBN) in pediatric oncology, and (2) to develop and weigh recommendations for BBN in pediatric oncology.
Methods: A mixed-methods Participatory Group Delphi (PGD) study was conducted to develop recommendations for the preparation, transmission, and follow-up of BBN. Practice-based evidence (PBE) was collected from four groups (N = 14 organizations) with different BBN experiences: (1) patient and family representatives, (2) healthcare providers, (3) psychosocial supporters, and (4) health services researchers.
Results: The PGD process (16 interviews, three focus group discussions and two surveys) resulted in 166 recommendations (preparation: 55; transmission: 45; follow-up: 66).
Conclusion: The PGD approach provided a structured framework for collecting PBE and developing, refining and consolidating recommendations on BBN in pediatric oncology. Involving all affected by BBN was crucial for addressing the complexity of BBN in the recommendations. The mixed-methods design enhanced the reliability and practical applicability of the recommendations.
Innovation: To our knowledge, no prior research in pediatric oncology has systematically integrated existing PBE into a structured set of recommendations in Germany. This study introduces a novel PGD process in this field in Germany, incorporating three key innovations: (1) a participatory methodology ensuring active stakeholder engagement, (2) a uniquely diverse expert panel including those affected by pediatric cancer, and (3) a systematic, iterative recommendation development approach rooted in PBE. This methodology results in a Delphi process that diverges significantly from classical approaches, offering a collaborative and structured framework for evidence synthesis.

1. Introduction

"Luckily it's not cancer!" This quote from a mother who just received her child's leukemia diagnosis highlights the challenge of Breaking Bad News (BBN) in pediatric oncology.

Cancer is the most common fatal disease and the second leading cause of death in children and adolescents (under the age of 18) [1]. In Germany, approximately 2200 children and adolescents are diagnosed with cancer annually, treated in over 60 pediatric oncology facilities nationwide [2]. This corresponds to an annual incidence of around 170 new cases per 1 million individuals under the age of 18 [1]. Given the profound impact of a cancer diagnosis, BBN conversations are crucial

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conversations that can negatively affect a patient's view of their future, such as discontinuation or modification of therapy [3].

BBN encompasses various critical disease situations that significantly impact the individual and their future, such as initial diagnosis, disease progression or recurrence [4].

In both adult and pediatric oncology, communicating a cancer diagnosis or similar serious information is perceived as particularly challenging for all parties involved [4,5]. The pediatric setting is unique in that it involves a 'trialogue' between three key stakeholders: the child/adolescent (BBN recipient), their family (parents or legal guardian; BBN recipient) and the healthcare providers (BBN transmitter). Each party is actively engaged in the BBN process, making it inherently participatory [6-8].

BBN is often described by BBN recipients as a highly emotional and overwhelming experience that affects their psychological wellbeing [5,9]. A lack of specialized communication skills, knowledge and support required by BBN transmitters can not only have a negative impact on the patients but also their support system and their treatment. For instance, poor communication can contribute to heightened psychological distress and reduced treatment adherence [10,11]. Furthermore, healthcare providers often experience significant emotional distress as BBN transmitter, perceiving those conversations as burdensome, isolating, and mentally exhausting [12,13]. Physicians face the challenge of balancing the delivery of crucial medical information while also addressing the emotional needs of BBN recipients [14]. This distress has been linked to reduced job satisfaction [15]. In the German pediatric oncology, there is a lack of formal training for healthcare providers (e.g., physicians or nurses) on effective BBN communication. The absence of structured education and ongoing training opportunities contributes to uncertainty and anxiety when conducting these conversations, potentially affecting the quality of patient-provider interactions [16].

Despite the urgency of this issue, pediatric oncology-specific BBN strategies remain largely underexplored, particularly in Germany. There is a notable lack of systematically developed tools for preparing interdisciplinary pediatric oncology teams for BBN. Most of the adult oncology protocols (e.g., SPIKES [17], ABCDE [18]; BREAKS [19]) were developed by academics or healthcare providers through a top-down approach. Their applicability and effectiveness in the pediatric setting have not been systematically investigated.

The project OKRA (Orientation Compass for Breaking Bad News in Pediatric Oncology) was initiated to bridge this gap by supporting BBN transmitters in the preparation, transmission and follow-up of BBN processes in trialogue settings [20]. Its aim is to develop a compass with a bottom-up approach, ensuring a practice-based, participatory framework. The OKRA project followed a two-phase mixed-methods design: (1) multi-perspective knowledge generation and development of recommendations and (2) design and real-world optimization of the OKRA compass. OKRA is a Germany-wide project that is funded by the umbrella organization "Aktion für krebskranke Kinder e.V." (English: "Action for children with cancer e.V."; DLFH).

This paper provides a detailed methodological account of Phase 1. Phase 2, which involved the practical implementation and refinement of the OKRA compass, has been published elsewhere [21].

This study (phase 1 OKRA) aimed (1) to gain a comprehensive, multi-perspective understanding of the preparation, transmission and follow-up of BBN in pediatric oncology, and (2) to develop and weight recommendations for BBN in pediatric oncology. In this paper, recommendations are assertions derived from the qualitative research process. These recommendations served as the foundation for the orientation compass, which was later refined and implemented in Phase 2.

However, the core contribution of this paper lies in its methodological approach. To generate these recommendations, a Participatory Group Delphi (PGD) approach was utilized. Traditional Delphi studies typically rely on structured professional expert consensus [22]. In Germany, seldom experts with their own experiences (e.g., patients) or patient representatives are engaged in "classic" delphi processes; and most of them are based on a questionnaire with no interaction between the participants [23]. Our PGD model introduced an innovative participatory approach, engaging stakeholders with diverse professional and experiential backgrounds in an interactive co-development process. This method fostered direct dialogue, iterative refinement, and co-learning, ensuring a comprehensive and practice-informed synthesis of evidence.

By focusing on the PGD method, this paper highlights how participatory techniques can be effectively adapted to ethically sensitive and emotionally charged fields like pediatric oncology. To our best knowledge, no participatory Delphi study of this nature has been conducted in Germany, making this research a methodologically and practically innovative contribution to pediatric oncology communication.

2. Material and methods

2.1. Study design

Practice-based evidence was generated through a PGD process, a methodological variant of the Delphi technique, which facilitates consensus-building among experts through structured group discussions [24,25]. Unlike the classical Delphi method, which relies on repeated rounds of anonymous questionnaires with limited direct interaction, PGD enables direct exchanges between participants, fostering dynamic discussions and immediate feedback loops [26]. This study employed a participatory framework within the Delphi methodology, ensuring a departure from traditional approaches. While classical Delphi studies rely on anonymous expert surveys [23], our PGD approach incorporated structured, real-time interactions, allowing for more nuanced and iterative knowledge synthesis. The diverse expert composition included patient and family representatives, healthcare providers, psychosocial professionals, and researchers, ensuring a transdisciplinary and holistic approach to knowledge integration.

For the OKRA PGD, a mixed-methods design combining qualitative and quantitative data collection was utilized. Data were systematically collected via semi-structured interviews (qualitative), focus group discussions (FGD) (qualitative) and online surveys (quantitative). The PGD process followed a structured six-step approach (Table 1) to develop, refine, and achieve consensus on recommendations.

In both FGDs and the consensus workshop, discussions occurred in rotating breakout groups (Table 1). Participants were assigned to one of three groups according to the division of the compass: preparation, transmission and follow-up of BBN. Each breakout group was

Table 1
Steps of the OKRA Participatory Group Delphi.

Step	Description	Participants	Method	Output
1	Semi-structured interviews	PGD participants	Interviews about expertise in BBN	Multi-perspective understanding
2	Focus group discussion	PGD participants	Discussion in small groups	Preliminary recommendations
3	Online survey	PGD participants + further individuals from PGD organizations	Evaluation and optimization of recommendations with Likert scale ratings	Modified and added recommendations
4	Focus group discussion	PGD participants	Discussion in small groups	Final recommendations
5	Online Survey	PGD participants + further individuals from PGD organizations	Likert scale ratings and weightings of recommendations	Prioritized final recommendations
6	Consensus workshop	PGD participants	Discussion in small groups	Consensual, final recommendations

interdisciplinary, ensuring representation from all four participant categories: patient and family representatives, healthcare providers, psychosocial supporters, health services researchers). To ensure balanced perspectives, groups rotated after Step 2, and in step 4 and 6, allowing each participant to contribute to all BBN sections.

2.2. Scientific research team

The scientific research team comprised two psychologists (HI, RD), one public health scientist (KT), one nursing scientist (DK) and one physician specializing in psychosomatic medicine, internal medicine, and communication training (VF). Each researcher brought expertise in key areas relevant to BBN, including psychology, psychosomatic medicine, healthcare development, nursing science, and public health.

2.3. Co-research team

The OKRA PGD enabled the analysis of BBN from multiple stakeholder perspectives. Participants, all with significant BBN-related experience, were categorized into four groups:

1) Patient and family representatives: Adults who had experienced BBN as children or adolescents, as well as parents of affected children or adolescents.
2) Healthcare Providers: Members of interdisciplinary pediatric oncology teams, including BBN transmitters and representatives of national pediatric oncology societies.
3) Psychosocial Support Organizations: Counselors and support professionals who assist families during BBN processes.
4) Health Services Researchers: researcher who provided methodological and healthcare system insights.

Participants were affiliated with 14 organizations or associations across Germany. Groups 1 to 3 each having four representatives, while group 4 consisted of two representatives, supplemented by the scientific research team's contributions.

2.4. Setting and mode of data collection

All qualitative data collection (e.g., interviews, FGDs, and the consensus workshop) was conducted online using the platform "ZOOM". The two online surveys were distributed using "LIME Survey". To comply with German General Data Protection Regulation (GDPR) standards, a secure "ZOOM" access and a GDPR-compliant version of "LIME Survey," provided by the University of Cologne, were utilized.

2.5. Data collection and analyses

The PGD was conducted between 11/2023 and 02/2024.

Step 1 – Interviews.

Semi-structured interview guidelines were developed, piloted, and refined with two co-researchers from Group 1 and 2 [27] (Appendix A). Interviews were tape-recorded, and handwritten notes were taken. Audio recordings were transcribed verbatim, rendered anonymous and analyzed by two researchers (DK, KT) using MAXQDA software [28]. Thematic analysis was conducted following Braun & Clarke's [29] six-step framework: familiarization with the data, inductive and deductive coding, category building, topic searching, verification, topic specification and preparation of analysis results. Each co-researcher (HI, DK, KT) initially coded transcripts independently, focusing on one of three BBN phases (preparation, transmission, follow-up). Each of them filtered out relevant statements, which we refer to as recommendations in the following process. Statements were adapted in terms of wording and language to make them concise and easy to read for the subsequent focus group discussion; for instance, filler sounds such as "um" were removed and long sentences were condensed to their core. The filtered statements were then discussed and debated in a joint meeting of the three co-researchers.

Step 2 and 4 – Focus Group Discussions.

Focus Group Discussions (FGD) were conducted via ZOOM, with one researcher (RD) providing technical assistance. After a joint introduction, all participants ($N = 19$), were divided into three breakout groups ($N = 5–6$) to further work and discuss the recommendations that emerged from the interviews, in step 2, these were called preliminary recommendations. Three research team members moderated the breakout groups, ensuring a democratic decision-making process (BBN preparation: DK, transmission: KT, follow-up: HI). Shared Google Docs were used for real-time editing and discussing the recommendations. In step 2, preliminary recommendations were displayed with frequency counts from the interviews, in step 4 from the survey, allowing participants to express agreement, disagreement, or propose refinements. In Step 6 (Consensus Workshop), participants rotated between BBN sections to provide input on all topics. FGDs were recorded, and concise handwritten notes were taken.

Step 3 and 5 – Surveys.

Survey content was developed based on insights from previous interviews and FGDs. The first survey allowed participants to accept, reject, or refine recommendations via free text input. In the second survey, a six-point Likert scale [30] was used to assess agreement levels (from "strongly agree" to "strongly disagree") with each recommendation [26], supplemented by free-text fields [31].

Socio-demographic data of the PGD participants and all participants in the online survey were recorded. Statistical analysis was performed descriptively, calculating means and standard deviations using SPSS 29 [32].

Step 6 – consensus workshop.

The second survey yielded the following results: the approval rate was grouped as "very important", "important" and "desirable", and each recommendation was labeled based on its practice-based evidence strength (Table 2). The scientific research team created these classifications through consensus discussions among themselves. The approval ratings were derived from responses from survey 2 (step 5), where participants indicated agreement percentages for each recommendation. The rating was calculated as a percentage of how many people agreed with a recommendation with 'strongly agree' or 'agree'. In the online consensus workshop, the final set of recommendations was refined and assigned a weighting based on survey results and expert discussion.

3. Results

3.1. Sociodemographic description of the PGD participants

The PGD participants had an average of 47.22 (SD = 9.89) years of age and an average of 19.16 years of expertise in BBN. Participants were located across Germany (Table 3) and represented 14 distinct organizations. Expertise and perspective on BBN varied, with most participants indicating multiple areas of expertise (Table 3). A total of 63.2 % ($n = 12$) had undergone additional training in BBN. Socio-demographic data for all participants in surveys 1 and 2 can be found in Appendix B.

3.2. Key findings

The PGD process yielded 166 collaboratively developed recommendations, organized into 26 categories aligned with the stages of BBN: preparation, transmission, and follow-up (Table 4).

Table 2
practice-based weight of the Breaking Bad News (BBN) recommendations.

Weight	very important	important	desirable
Label	↑↑	↑	↔
Approval rating	>90 %	90–70 %	<70 %

Table 3
Sociodemographic data of the OKRA Participatory Group Delphi participants.

	Total sample	
	n	%
Sex		
Female	12	63.2
Male	7	36.8
Highest professional qualification		
Vocational education	4	21.1
University degree of applied sciences	1	5.3
University degree	8	42.1
Postgraduate qualification	6	31.5
Federal state of Germany		
Bavaria	3	16.7
Hessen	1	5.5
Lower Saxony	2	11.1
North Rhine-Westphalia	8	38.9
Rhineland-Palatinate	3	16.7
Saxony	2	11.1
Context with BBN (multiple responses)		
Hospital	12	26.1
Professional association	4	8.7
Self-help	5	10.9
Outpatient sector	5	10.9
Domestic environment	2	4.3
Association	6	13.0
University	4	8.7
Not specified	2	4.3
Other	6	13.0
Expertise in BBN (multiple responses)		
Therapy	8	10.7
Nursing Care	5	6.7
Nursing politics	14	18.7
Psychosocial support	10	13.3
Process support & orientation	10	13.3
Family support & emotional support	13	17.3
Counseling (e.g., psychological)	7	9.3
Research	3	4.0
Trialogical communication	2	2.7
Not specified	1	1.3
Other	2	2.7

Table 4
Categories of BBN preparation, transmission and follow-up phases.

BBN Part	Categories
1. Preparation	1.1. Family-specific knowledge
	1.2. BBN supporter
	1.3. Presence of children
	1.4. Organization of the appointment
	1.5. Setting and materials
	1.6. Disease-specific knowledge
	1.7. Conversational structuring
	1.8. BBN knowledge and skills
	1.9. Personal attitude of the BBN transmitter
2. Transmission	2.1. General conditions
	2.2. Conversation start
	2.3. Multi-professional role definition & understanding
	2.4. Key components first consultation
	2.5. Key components second consultation
	2.6. Structural support for BBN first and second conversations
	2.7. "Good" closing of the conversation
	2.8. Support & success factors
3. Follow-Up	3.1 Coping strategies and enhancing communication
	3.2 Support for parents for family talks
	3.3 Managing potential trauma in the family
	3.4 Psychosocial support in inpatient stay
	3.5 Social law counseling options
	3.6 Information material
	3.7 Networking options
	3.8 Quality enhancement aspects
	3.9 Processing and coping strategies

This section emphasizes how iterative co-creation shaped and refined these outputs. Initially, 177 recommendations emerged from interview coding. Through multiple feedback loops and consensus-building steps, this number was reduced and sharpened to a finalized set of 166 recommendations (Table 5).

Each step of the PGD involved active integration of participant expertise and iterative validation of the proposed content. The average importance level assigned by participants remained high across all BBN phases, reflecting the perceived relevance of the co-developed outputs. Appendix C includes an overview of the final recommendations; however, detailed analysis of their content is beyond the scope of this paper. For further information see Dittmer et al. published in PEC [21].

3.3. Results of the PGD per step

Step 1: Interviews.

The 16 interviews had an average duration of 78 min (range: 49 to 113 min). A total of 1241 min of audio material was transcribed, producing 1860 coded segments grouped into 431 codes. Two authors (DK, KT) collaboratively synthesized inductive and deductive codes into 26 categories (Table 5), which remained constant throughout the PGD process.

This early phase laid the foundation for recommendation generation by combining systematic qualitative coding with researcher triangulation to ensure methodological rigor. A total of 177 preliminary recommendations were formulated across the BBN process phases.

Step 2: Focus group discussion 1.

During the first FGD (1.5 h), participants reviewed the preliminary set of 177 recommendations and engaged in structured group work to assess redundancy, clarity, and feasibility. This led to the removal or merging of 16 recommendations and the addition of two new ones, resulting in 163 total recommendations at this stage (Table 5).

The discussion illuminated areas of conceptual tension, surfacing four topics that required further clarification and consensus. These early conflicts highlighted the diversity of perspectives and the value of real-time negotiation in shaping meaningful guidance.

Step 3: Survey 1.

In survey 1, 29 participants rated the 163 recommendations, reflecting their degree of development (Fig. 1). Importantly, the survey provided space for feedback and new inputs, reflecting the participatory design. This resulted in 26 new proposals and 15 rejections, bringing the updated total to 174 recommendations. The process ensured that emerging voices and practical concerns were incorporated midstream.

Step 4: Focus group discussion 2.

During FGD 2 (75 min), survey results were discussed, and recommendations were accepted, revised, or rejected based on predefined thresholds (Fig. 1). Specifically, 136 (78.16 %) were accepted, 30 (17.24 %) were modified, and 8 (4.60 %) were rejected. The research team guided the discussion using a combination of quantitative ratings and qualitative reasoning, applying a consensus-driven model for decision-making.

New thematic emphases emerged, demonstrating the ongoing evolution of content in response to participant feedback and group dynamics.

Step 5: Survey 2.

Survey 2, with 34 participants, was used to rate the refined set of 166 recommendations from FGD 2 (Table 5) using a 6-point Likert Scale, with higher scores indicating greater agreement:

- BBN preparation: mean = 5.29 (SD = 0.78)
- BBN transmission: mean = 5.39 (SD = 0.46)
- BBN follow-up: mean = 5.32 (SD = 0.49)

This validation step quantitatively confirmed the level of agreement across diverse stakeholder groups, reinforcing the legitimacy and robustness of the co-developed guidance.

Table 5
OKRA recommendations development in the Participatory Group Delphi.

Steps	Method	BBN phases	Number of recommendations				
1	Interviews	Preparation	67				
	(N = 19*)	Transmission	42				
		Follow-Up	68				
		Total	177				
2	Focus group discussion 1			Accepted	Optimized	Rejected	New
	(*N* = 18*)	Preparation	59	41	17	9	1
		Transmission	42	25	17	0	0
		Follow-Up	62	51	10	7	1
		Total	163	117 (66.10 %)	44 (24.86 %)	16 (9.04 %)	2
3	Survey 1 (*N* = 29*)			Accepted	Optimized	Rejected	New
		Preparation	56	30	23	6	3
		Transmission	49	21	18	3	10
		Follow-Up	69	35	21	6	13
		Total	174	86 (52.76 %)	62 (38.04 %)	15 (9.20 %)	26
4	Focus group discussion 2 (N = 19*)			Accepted	Optimized	Rejected	New
		Preparation	55	49	6	1	0
		Transmission	45	35	10	4	0
		Follow-Up	66	52	14	3	0
		Total	166	136 (78.16 %)	30 (17.24 %)	8 (4.60 %)	0
5	Survey 2 (*N* = 34*)			Accepted			
		Preparation	55	55			
		Transmission	45	45			
		Follow-Up	66	66			
		Total	166	166			
6	Consensus workshop (N = 19*)			Accepted			
		Preparation	55	55			
		Transmission	45	45			
		Follow-Up	66	66			
		Total	**166**	166			

Note: * The 19 participants in the Delphi process took part in the discussion rounds, except for FGD 1, where one participant was unable to attend. Other employees from the participants' organizations took part in the surveys.

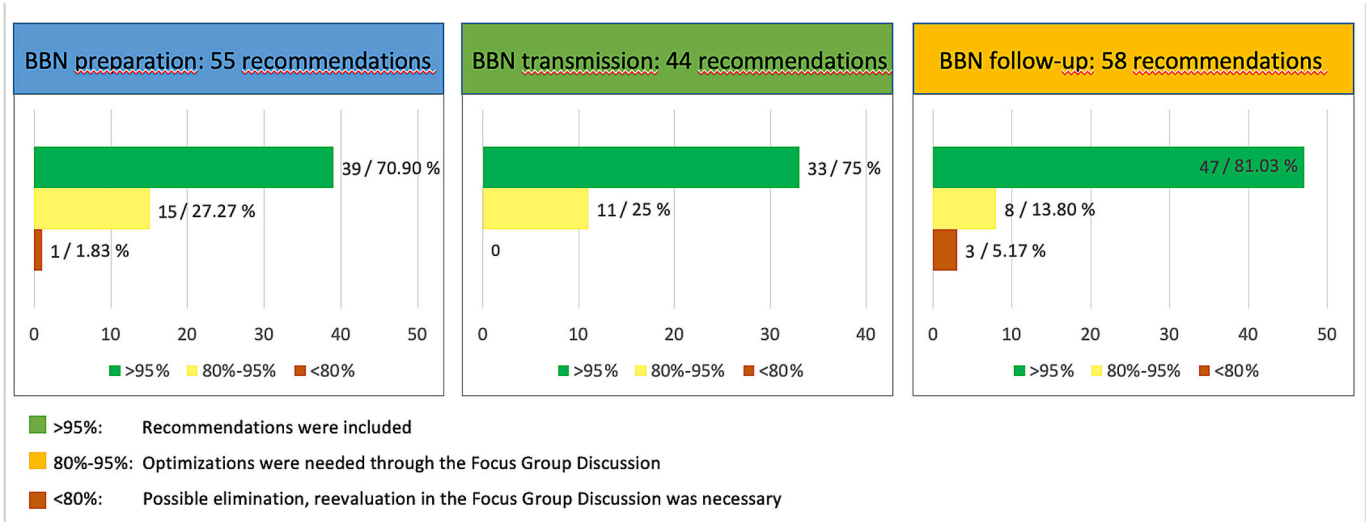

Fig. 1. Survey 1 exploring the degree of development of the OKRA recommendations during the Participatory Group Delphi.

Step 6: Consensus Workshop.

In the final stage (60 min), the considered recommendations were refined and categorized (Table 5). Of 166 recommendations (Fig. 2):

- 88 were classified as "very important".
- 68 were classified as "important".
- 10 were classified as "desirable".

Cut-off values and categorization terms were discussed and agreed upon with the co-research team.

The workshop solidified shared ownership of the outputs and marked the transition from recommendation development to practical application. Categorization criteria were defined collaboratively, ensuring that final classifications reflected both empirical support and experiential insight. Participants emphasized the foundational role of these recommendations in the subsequent development of the BBN orientation compass (Phase 2).

4. Discussion and conclusion

4.1. Discussion

This Phase 1 study systematically developed key recommendations for BBN, emphasizing participatory research and PBE. In the following,

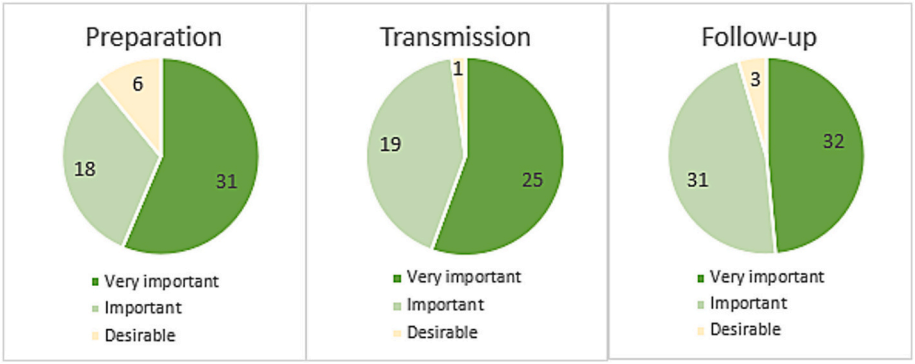

Fig. 2. Consensus of the OKRA recommendations for Breaking Bad News in the pediatric oncology.

we highlight the key benefits of this approach. To the best of our knowledge, our study is the first to generate knowledge concerning the experiences and needs for BBN in pediatric oncology from four expert perspectives: (1) patients and family representatives, (2) healthcare providers, (3) psychosocial supporters, and (4) health services researchers.

We have systematically uncovered and integrated the valuable "treasure chest" of practice-based evidence, ensuring its relevance and applicability within the German pediatric-oncology context. A consistently applied bottom-up participatory approach fostered a co-learning environment and empowered all members of the co-research and professional research team. The PGD method, combined with mixed-methods data collection, facilitated an iterative process for discovering, formulating, maturating and weighing recommendations. This structured and inclusive process ensures that the results are not only methodologically sound but also directly relevant to clinical practice. This gradual and participatory approach led to practicable recommendations suitable for the German context. The following sections discuss the key results in detail.

4.1.1. Gaining a multi-perspective and nationwide understanding of BBN needs

The integration of diverse perspectives was a key feature of this study, ensuring a holistic and contextually grounded approach in developing BBN recommendations. Participants from across Germany contributed to a nationwide, multi-perspective understanding and broad spectrum of insights and experiences, enriching the recommendations with experiential knowledge. Dynamic interactions and iterative feedback mechanisms, such as FGDs and surveys [33], allowed for in-depth discussions and consensus-building on critical aspects of BBN, including family-specific knowledge, interdisciplinary role clarity, and transparent parent-child communication.

Key controversial issues, such as whether children should be present during the initial BBN conversation, were thoroughly discussed until consensus was reached, leading to well-balanced, evidence-based recommendations.

One agreed upon recommendation was that parents should first receive the consultation to process the information before informing the child shortly afterwards (recommendation 12, Appendix C). This is consistent with the results of an American study [34]. Further, an interdisciplinary team, not just one physician, should prepare, conduct and follow-up on BBN (recommendation 7 & 8, Appendix C) [35]. Another key finding emphasized the importance of pausing during BBN consultations (recommendation 93, Appendix C). Additionally, intercultural communication and awareness of the family's backgrounds were identified as crucial factors in BBN preparation (recommendation 9, Appendix C). In line with the results of a British study, the recommendations do not include comforting as a transmitter but rather giving parents and the affected child space for their emotions, allowing silence and communicating important information (recommendation 38, 81, 94, Appendix C) ([36].

Unlike most Delphi studies in pediatric oncology, which often rely on a narrower range of expert opinions, e.g. academics or practitioners [37-39], our study deliberately incorporated diverse stakeholder perspectives, ensuring that practice-based insights, rather than solely theoretical expert assumptions, shaped the final recommendations. By integrating PBE, this study enhances transparency, inclusivity, and practical relevance in BBN guidance [40].

4.1.2. Reflections on the bottom-up recommendations development process

Conventional Delphi studies often face challenges such as participants' drop-outs, which can weaken the validity of consensus-building [41,42]. In contrast, our study achieved high participant engagement, indicating a strong demand for a structured, systematic practice-based guidance instrument. The iterative PGD process facilitated deep collaboration, ensuring that each recommendation was methodically refined, validated and contextually grounded.

Unlike other settings (e.g., Swiss [43], French [44]), the participatory, bottom-up approach was innovative for German pediatric oncology. The research team provided co-researchers with theoretical and methodological training, ensuring informed participation [45]. No participants withdrew from the study; several participants described the PGD process as "empowering" with valuable "co-learning moments". Collaboration was perceived as "stimulating" and "eye-opening". The absence of participant drop-outs and the positive feedback underscore the efficacy and relevance of this participatory approach.

Despite its strengths, participatory approaches require significant time and resources, leading to well-accepted outcomes [46-48]. While this study demonstrated the feasibility of participatory research in pediatric oncology, the lack of financial compensation for co-researchers highlights an area for improvement in future funding models in Germany [49,50].

Participation develops over time [51]. A novel methodological aspect of this study was the systematic assessment of participation intensity. During the consensus workshop (PGD, step 6), the co-researchers reflected on their involvement using the Participation Net framework [52] which features six rings indicating participation intensity (Fig. 3). The center shows the classic project cycle in health system research: Orientation, Conceptualization, Preparation, Data Collection, Analyses, Interpretation of Analyses, and Dissemination/Transfer.

Fig. 3 provides a visual summary of the participatory process, highlighting its methodological contribution. It illustrates how participation was not only sustained but deepened across project phases.

Data entry was interactive, guided by the scientific research team, using Google Docs for participants to reflect their subjective experiences (Fig. 3). Two key observations emerged: the consistency of responses within individual groups across project phases and consistency of

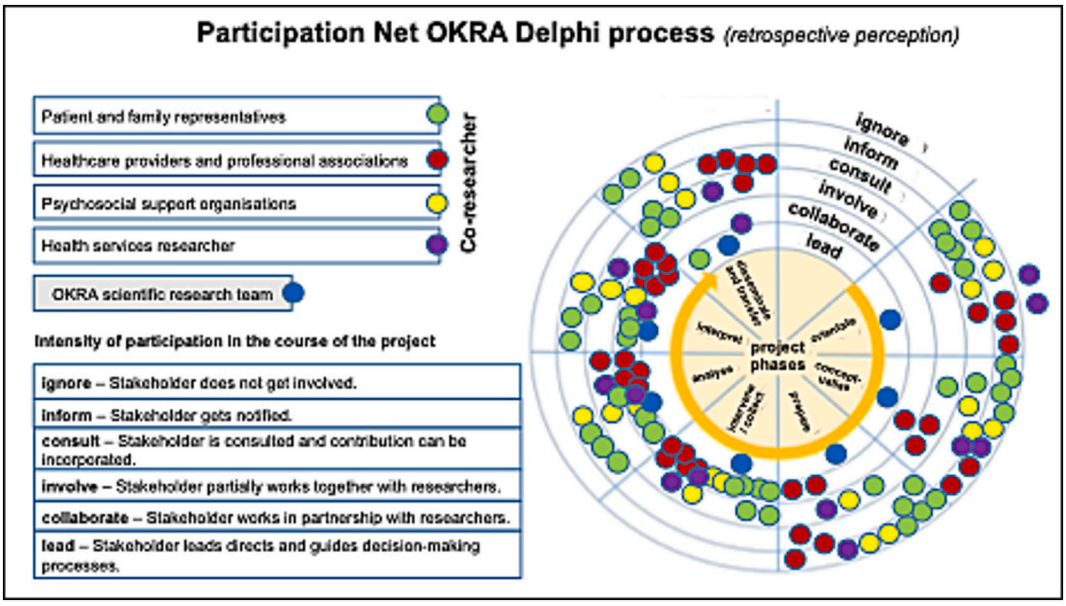

Fig. 3. Participation network of the OKRA participatory group Delphi.

responses among different groups. Fig. 3 shows that all groups perceived high participation intensity and felt equally involved, regardless of research experience or professional background. This consistency further supports the reliability of the participatory process and the shared perception of meaningful involvement.

Unlike conventional Delphi studies, that primarily aggregate expert opinions, our study introduced a dynamic, iterative approach that enhanced interdisciplinary collaboration, knowledge exchange, and robust recommendation maturation.

4.1.3. Stepwise and mixed methods maturing of the recommendations

The OKRA recommendations were developed using a structured, six-step process, combining qualitative and quantitative methodologies. This stepwise approach involving interviews, FGDs, and surveys, leveraged the unique strengths of each [53]. This stepwise refinement ensured systematic validation, adjustment, and endorsement across all stakeholder groups.

Unlike other Delphi studies that rely on a single method (e.g., surveys, [41,54]), our mixed-methods approach allowed for iterative refinements via FGDs and consensus-building surveys. This approach ensured that recommendations remained responsive to participant input, leading to final recommendations that were rigorously vetted and widely endorsed.

4.1.4. Strengths and limitations

The six-step PGD was completed within 4.5 months, demonstrating an efficient yet comprehensive participatory research process. The compressed timeline required structured project coordination and active collaboration from all participants. The compressed schedule for interviews, FGDs, and surveys necessitated reliable teamwork and strict timeline adherence. A "master plan" was approved by co-researchers early on, though some missed discussions due to urgent pediatric ward needs, health issues, or holidays. Despite this, high commitment from all 19 PGD participants resulted in no dropouts, consistent with previous PGD experiences [55-57].

Following established mixed-methods quality standards [53], we prioritized credibility through triangulation and systematic refinement. While the PGD process was inclusive, some perspectives may have been underrepresented, due to regional differences, as participants came from only six of 16 federal states. However, involving professional society representatives enhanced representativeness and generalizability. The co-researchers' involvement in shaping the recommendations increased confirmability [53].

We used a combined approach, as recommended for mixed methods [53], to enhance the acceptability of the recommendations. Our goal was to achieve a comprehensive understanding rather than saturation.

The exclusively online format of this PGD had both strengths and limitations. While it enabled cost-effective nationwide participation [58], it may have constrained the depth of spontaneous discussion compared to in-person settings [59]. The online format also effectively facilitated participation from geographically dispersed and resource-limited individuals, making it a viable model for future participatory studies [60]. This approach required participants to have technical skills for online meetings and a research team trained to handle online data collection challenges.

4.1.5. Practice implications

The matured recommendations represent Germany's first structured, practice-based evidence framework for BBN in pediatric oncology. These recommendations offer essential, field-tested guidance for healthcare providers and BBN recipients. They offer a comprehensive understanding of the BBN needs of transmitters and recipients. The major outcome of OKRA is the establishment of the Orientation Compass, which, in Phase 2, was further refined into a widely accessible, implementation-ready instrument, available for all pediatric oncology departments across Germany.

4.2. Innovation

Delphi studies in (pediatric) oncology typically rely on literature reviews and theoretical frameworks [38,61-63]. To our knowledge, no prior research in pediatric oncology has systematically compiled and synthesized existing practical-based evidence (PBE) into coherent recommendations. This study introduces three key innovative elements that differentiate it from traditional Delphi studies: (1) the participatory process of the Delphi, (2) the composition of the expert panel, and (3) the development of recommendations based on PBE.

Firstly, the participatory nature of the Delphi process is a novel approach, actively involving both researchers and those directly affected by the outcomes. This approach allows for a more inclusive and dynamic decision-making process, where the insights and practical experiences of participants significantly shape the results. Secondly, the expert panel

composition is unique, consisting of individuals with substantial hands-on experience in the field, ensuring that the recommendations are deeply rooted in real-world practice rather than theoretical models. Lastly, the recommendations developed through this process are based on PBE, which provides a more reliable and stable foundation for practice compared to traditional evidence that relies solely on theoretical or literature-based findings.

In Germany, a shift towards valuing PBE is necessary. Green et al. [64] emphasized "If we want more evidence-based practice, we need more practice-based evidence". Success requires sharing power and welcoming engagement in decision making [65]. We experienced practice-based research partnerships between researchers and those affected (BBN transmitters and receivers) both valuable and feasible [66]. By valuing the input of our participants, who have an average of 19.1 years of experience, we have enriched the understanding of BBN with practical solutions that bridge the research-practice gap [67] and foster a shift from merely capturing existing practices to actively creating them [68]. The resulting systematically developed recommendations provide highly relevant and applicable insights for everyday clinical practice, which form the basis for the next phase of our research: the development of the 'compass.' This next phase will build upon the recommendations to establish a more structured framework, where the recommendations developed here will form the base for further research. The innovative nature of our approach is crucial for ensuring a reliable and applicable foundation for phase 2.

4.3. Conclusion

Our PGD in OKRA promotes advances in BBN in pediatric oncology as diverse perspectives, e.g. from patient and family representatives, healthcare providers, and researchers, were incorporated in the recommendations.

Recruiting participants from across Germany ensured a comprehensive nationwide understanding. Valuing contributions from all groups, it leveraged their strengths in BBN. The recommendations were systematically developed using a participatory, bottom-up approach with various methods for robustness and applicability. By combining participatory research principles with a structured Delphi approach, this study has established a validated and reliable foundation for phase 2 of the OKRA project. The unique interplay of participatory methodology, transdisciplinary expert composition, and systematic practice-based evidence synthesis ensures that the Orientation Compass will be a widely applicable, context-sensitive, and methodologically robust tool for pediatric oncology in Germany.

CRediT authorship contribution statement

Isabel Hamm: Writing – original draft, Validation, Supervision, Resources. **Kerstin Dittmer:** Writing – review & editing, Visualization, Validation, Resources, Investigation. **Frank Vitinius:** Writing – review & editing, Validation, Methodology, Investigation, Funding acquisition, Conceptualization. **David Reinert:** Writing – review & editing, Validation, Resources, Investigation. **Marc Hoemberg:** Writing – review & editing, Resources, Investigation. **Remo Kamm-Thonwart:** Writing – review & editing, Investigation. **Rainer Misgeld:** Writing – review & editing, Resources, Investigation. **Theresia Krieger:** Writing – review & editing, Visualization, Validation, Resources, Project administration, Methodology, Funding acquisition, Conceptualization.

Consent for publication

All authors hereby give consent for the publication of this manuscript titled in the Journal Patient Education and Counseling. We confirm that all the necessary permissions for the use of any third-party materials have been obtained.

Ethics approval and consent to participate

This study was approved by the Ethics Committee of the Faculty of Medical at the University of Cologne (No. 23–1187) and adhered to the principles of the Declaration of Helsinki and relevant national and European data protection regulations. Before data collection, the researchers provided written and oral information to each participant, explaining the study's procedures and objectives. Written informed consent was then obtained from each participant.

Trial registration

German Clinical Studies Register (https://www.drks.de/DRKS00031691

No. DRKS00031691, Date of registration: 17.01.2024).

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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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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2025.100413.

Data availability

Due to the sensitive nature of the questions asked in this study, the respondents were assured that the raw data would be kept confidential and not be shared.

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