

Bridging the gap: A quality improvement project to implement psychosocial care standards into clinical practice in pediatric oncology

Die Lücke überwinden: Ein Qualitätsverbesserungsprojekt für psychosoziale Standards in der pädiatrischen Onkologie



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Key words

implementation research, quality improvement, evidence – and consensus-based guidelines, pediatric oncology, patient-centered care, therapy optimization

Schlüsselwörter

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ABSTRACT

Background Psychosocial guidelines and standards systematically describe stressors and resources in particularly challenging situations and hence serve as a basis for interventions to achieve defined psychosocial goals. Despite fundamental principles and guidelines for psychosocial methods, the quality of provided care varies considerably depending on setting, provision, and profession. The purpose of the present protocol is to illustrate the development and evaluation of the standardized psychological intervention “My Logbook”, a practical guide accompanying children through all stages of treatment by directly translating current quality standards of psychosocial care into practice.

Methods In an evidence-based set-up, using face-to-face discussions and telephone conferences, a multi-professional team of local experts decide on critical disease-related issues, structure, content (information and intervention elements) and design of the quality improvement tool. Via delphi surveys an extended expert team is asked to rate the content, method, and design of all booklets which is concluded by a final agreement by the specialist group for quality assurance of the psychosocial working group in the Society for Pediatric Oncology (PSAPOH). The developed tools are piloted in an international multicenter study to evaluate the patient-reported outcome and feasibility and to integrate practical views of patients, as well as psychosocial and interdisciplinary professionals into the further development of the “My Logbook”.

Discussion The iterative development of the “My Logbook” including local and international experts as well as the patient and practical perspective allow for the design of a process-oriented, consensus – and evidence-based tool directly translating the S3-Guideline into clinical practice. Feasibility and applicability are fostered through an iterative process of constant evaluation and adaptation of the tool by international experts and through the clinical experience gathered in the multi-centered pilot study. Furthermore, the systematic evaluation of the tool by patients, psychosocial, and interdisciplinary professionals enables the identification of persisting gaps between evidence-based standards and clinical practice, discrepancies between the various stakeholders’ perspectives as well as regional differences in feasibility, thereby directly linking practice and research. The preliminary results emphasize that psychological support can be standardized, enabling an evaluation and optimization of psychosocial care which future studies need to assess in multi-center clinical randomized controlled trials.

ZUSAMMENFASSUNG

Hintergrund Psychosoziale Leitlinien und Standards beschreiben systematisch Ressourcen und Belastungen in besonders herausfordernden Situationen und dienen somit als Grundlage für Interventionen zur Erreichung definierter psychosozialer Ziele. Trotz definierter Grundprinzipien und evidenz- und konsensbasierter Leitlinien für psychosoziale Methoden variiert psychosoziale Versorgung je nach Setting, Angebot und Profession erheblich. Ziel der vorliegenden Studie ist es, die Entwicklung und Evaluation des standardisierten psychologischen Tools darzustellen: “Mein Logbuch” als ein praktischer Leitfaden, der Kinder durch alle Phasen der Behandlung begleitet, indem aktuelle Qualitätsstandards der psychosozialen Versorgung in ein patient:innenorientiertes Tool für die Praxis übersetzt werden.

Methoden Im Rahmen eines evidenzbasierten und interdisziplinären Ansatz definieren Fachexpert:innen in persönlichen

Gesprächen und Telefonkonferenzen über kritische krankheitsbezogene Fragen, Struktur, Inhalt (Informations – und Interventionselemente) und Design des Quality Improvement (QI) Tools. Mittels Delphi-Befragungen wird ein erweitertes Expert:innenteam gebeten, den Inhalt, die Methode und das Design aller Broschüren zu bewerten, was mit einer endgültigen Vereinbarung durch die Fachgruppe für Qualitätssicherung der psychosozialen Arbeitsgruppe in der Gesellschaft für Pädiatrische Forschung (PSAPOH) abgeschlossen wird. Das entwickelte Instrument wird in einer internationalen Multicenterstudie erprobt, um patient:innenorientierten Outcome sowie Durchführbarkeit zu evaluieren und damit Perspektiven durch Patient:innen sowie der psychosozialen und interdisziplinären Fachkräfte gleichermaßen in die Weiterentwicklung des “Mein Logbuch” einzubeziehen.

Diskussion Die iterative Entwicklung des “Mein Logbuch” unter Einbeziehung lokaler und internationaler Fachexpert:innen sowie der Patient:innen – und Praxisperspektive ermöglicht die Gestaltung eines prozessorientierten, konsens – und evidenzbasierten Instruments zur direkten Umsetzung der S3-Leitlinie in die klinische Praxis. Machbarkeit und Anwendbarkeit werden durch einen iterativen Prozess der ständigen Bewertung und Anpassung des Instruments durch internationale Fachexpert:innen und durch die in der multizentrischen Pilotstudie gesammelten klinischen Erfahrungen gefördert. Darüber hinaus ermöglicht die systematische Bewertung des Tools durch Patient:innen, psychosoziale und interdisziplinäre Fachkräfte die Identifizierung bestehender Lücken zwischen evidenzbasierten Standards und der klinischen Praxis, Diskrepanzen zwischen den verschiedenen Perspektiven der Beteiligten sowie regionale Unterschiede in der Durchführbarkeit, wodurch eine direkte Verbindung zwischen Praxis und Forschung hergestellt wird. Die vorläufigen Ergebnisse unterstreichen, dass psychologische Unterstützung standardisiert werden kann, was eine prozessbegleitende Evaluierung und Optimierung der psychosozialen Versorgung ermöglicht. Dies soll künftig in multizentrischen klinischen, randomisierten und kontrollierten Studien untersucht werden.

LIST OF ABBREVIATIONS

PSAPOH	Psychosocial working group in the Society for Pediatric Oncology and Hematology (German: Psychosoziale Arbeitsgemeinschaft in der Gesellschaft für Pädiatrische Onkologie und Hämatologie)
EBP	Evidence-based practice
QI	Quality improvement
S3	Guideline for psychosocial care in pediatric oncology

PDSA	Plan-Do-Study-Act cycle
SDQ	Strengths and difficulties questionnaire
KINDL-R	Revised Questionnaire for children and adolescents to measure health-related quality of life [Revidierter Fragebogen für KINDer und Jugendliche zur Erfassung der gesundheitsbezogenen Lebensqualität]
PPPHM	Pediatric Psychosocial Preventative Health Model
WISC-V	Wechsler Intelligence Scale for Children – 5 th edition

Background

Prior research on the quality of care in pediatric oncology has clearly shown that psychosocial care is a fundamental standard in the treatment of children diagnosed with cancer. To ensure for the

quality and homogeneity of the psychosocial interventions, evidence – and expert-based standards and guidelines have been established during the past decade [1, 2]. Consequently, standards for the implementation of the methods used in psychosocial care should be emphasized. However, although cancer centers in the

United States [3] as well as German-speaking countries [4] claim to follow the standards for psychosocial care, an implementation study by Scialla et al. showed that only half of the doctors and psychosocial management stated that their care was comprehensive or state of the art [5]. Authors like Giesler et al. note that even if most cancer centers are providing the services as required, they differ considerably in the extent to which they fulfill the quality standards [6]. Particularly the personnel domain is commonly underdeveloped with a lack of service hours for psychologists, insufficient supervision, and case conferences as well as distress-screening and systematic documentation [6]. Furthermore, referral practices of doctors need improvement, since only about 36 % of patients who reported wanting psychosocial support received a referral [7] and only 29 % of all cancer patients received psychosocial care [8], with adolescents and young adults being especially underserved [9].

Hence, despite innumerable studies evaluating the efficacy of psychological interventions such as traditional cognitive behavioral treatment, relaxation trainings, or individual therapy, there seems to be a lack of clarity on how these standards and guidelines can be implemented, preventing psychologists' duty of acting to the best of one's knowledge [10]. On the one hand, this can be explained by the fact that the experimental designs used in most of these studies focus on isolated interventions detached from the psychosocial process. However, the usability and efficacy of single interventions depends on various factors interacting in a complex process, which is why psychosocial interventions need to be viewed in the context they are used in, imbedded in a comprehensive psychosocial process [2, 11, 12]. On the other hand, this complex clinical context is a multi-professional one, with each discipline having different research and practical priorities leading to discrepancies in the daily practice where all the different professionals come together to work with the same patient [13]. Finally, in the health care sector treatment decisions are always a balancing act between patient-oriented and research-focused or evidence-based decisions and it has proven difficult to put novel research findings into practice while also tailoring these standardized procedures to each individual with all their needs and specific circumstances [14]. However, considering the increasingly dynamic and resource-constrained conditions healthcare systems work in, basing clinical practice and new interventions on the most recent scientific knowledge is essential to maximize the benefit research investments have for healthcare value and hence public health [4]. Therefore, researchers such as Scialla et al. emphasize the need for more integrated models of psychosocial services developed by multidisciplinary expert groups as well as measures to implement them [5]. Only by bridging the gaps between evidence-based standards and clinical practice as well as between different health care professions, the maximal quality of effective consensus – and evidence-based yet patient-centered care can be achieved [13, 15, 16].

Since the movement of evidence-based practices (EBPs) into clinical routines is not spontaneous but is a long process requiring focused efforts, the field of implementation science has been developed [17]. It is considered to be a critical tool to facilitate the dissemination of EBPs, including both psychosocial and medical interventions for mental and physical health concerns [17, 18]. Due to the iterative nature of methods such as Plan, Do, Study, Act

(PDSA) cycles [18], evidence-based standards and clinical practice can be linked, which is why quality improvement (QI) projects are a promising approach for achieving faster and more effective implementation of evidence-based psychosocial standards and guidelines into the daily clinical routine [16, 18]. Furthermore, continuously evaluating such projects in a standardized manner would allow for the direct comparison of these novel interventions [17]. Open access data bases and QI publications would additionally ensure for more transparency and provide health care professionals with practical guidance through the experience of researchers in their field. This open spread of knowledge can also help counter systematic disadvantages and health inequity due to regional and personnel disparities among cancer centers, which are not only prevalent in medical care but especially in mental health care [19–22]. Overall, QI studies are hence believed to be a valuable tool for putting scientific knowledge into practice, not only providing professionals with the proof for the efficacy of certain guidelines, standards, and interventions, but also showing how to effectively make use of evidence-based standards in clinical practice, thereby ensuring that every patient experiences the best possible quality of care based on the current state of research [17, 18].

In German-speaking countries (Austria, Germany, Switzerland, South Tyrol in Italy) the consensus – and evidence-based S3-Guidelines function as a gold standard for psychosocial care in oncological pediatric therapy. The guideline structures the patients' needs and corresponding psychosocial interventions, defines quality standards and guarantees psychosocial care for children, adolescents and young adults with cancer and their families [1]. Another example of quality assurance in psycho-oncological care is the German certification agency *Onkozert* recommending a care ratio of one psychosocial professional for 22 patients as a certification criterion for cancer centers [23, 24]. In practice the specifics of this care are currently quite heterogeneous across oncological centers. Psychosocial teams vary substantially in size and professional constitution. This heterogeneity is caused by multiple factors such as the specific kinds of therapy provided by the hospital (e. g., proton therapy, aftercare), the stages of patients' condition at hospitalization, the communication culture in different professional groups, the magnitude and source of funding received by the center, as well as the country's legal and political environment [7, 8]. So far, only few QI studies have addressed psychosocial care in pediatric oncology [25–29].

The purpose of the present study is hence to describe the development, implementation, and evaluation of a tool that integrates psychosocial evidence-based methods into the multi-professional, interdisciplinary context of pediatric oncology. By translating the consensus – and evidence-based S3-Guidelines into clinical practice, the tool "My Logbook" aims to serve as a practical guide for psychosocial care, ensuring that all young patients receive the same quality of care throughout all stages of treatment, while also allowing for patient-centered adaptations of all interventions to achieve individual adequacy. Furthermore, the systematic recording of patient-reported outcomes and the feasibility of its application aims to assess the persisting gaps between evidence-based standards and care practice as well as to integrate the patient, psychosocial, and interdisciplinary perspectives into the development of the tool in an iterative process. The description of the development by a multi-professional team and evaluation by

patients and professionals in a multi-centered pilot phase will allow for a comprehensive insight into the steps necessary to create consensus – and evidence-based yet patient centered tools for high quality psychosocial care in pediatric psychology.

Methods

Basic principles

The present project “My Logbook – I know my way around!” aims to directly translate the S3-Guideline [1] into a patient-oriented tool for clinical practice in pediatric oncology and hematology. To this end, the theoretical recommendations in the *consensus – and evidence-based* psychosocial S3-Guideline are converted into practical instructions for selected disease-, treatment-, and process – related topics, categorized into six treatment phases, namely 1) *initial contact*, 2) *base-line assessment*, 3) *supportive therapies and counselling*, 4) *process-oriented diagnostics*, 5) *rehabilitation*, and 6) *follow-up care* [1, 30]. On the one hand, this translation shall facilitate the *implementation* of the S3-Guideline to *standardize and improve the quality of psychosocial care* in oncology and hematology, by facilitating *organization and planning*, increasing its *objectivity and transparency*, and reinforcing *interdisciplinary collaboration*. Thereby, the *practice-oriented instructions* have the potential to *optimize efficiency* regarding *personnel and material resources* and the conduct via psychosocial professionals shall ensure the *patient-centered adaptation* of care to each individual’s needs. On the other hand, the operationalization of recommendations paves the way for the *evaluation* of the feasibility and efficacy of the “My Logbook” as a patient-oriented tool. Hence the entire project is based on four core principles to bridge the gap between evidence-based standards and clinical practice, namely: *psychosocial expertise*, *patient-centered approach*, *standards for basic care with individual adaptations*, and *evaluation of efficacy for therapy optimization* [31].

The concept for the present study was first proposed to the board of PSAPOH (Psychosocial working group in the Society for Pediatric Oncology) as well as to the working group for quality assurance of PSAPOH. Both supported the patient-oriented development of a good clinical practice tool for selected issues in pediatric oncology and hematology by the research team of the Medical University of Vienna. Moreover, they strongly supported the involvement of the PSAPOH community for dissemination, conferences, and invitations for the *extended expert team* (as well for developmental but also multicenter implementation requests).

Procedure

For this QI project, a multi-level approach was used for the development, evaluation, and implementation and involved different expert and research groups. The *local expert team* comprising clinical psychologists and clinical social workers, conceptualizes the project, develops the content and design, evaluates the consecutive versions of the tool, and integrates feedback in the revisions. The second strain is the *extended expert group* including the *specialist group for quality assurance (PSAPOH)*, who evaluates the drafts, gives feedback and input for the improvement of the versions, and decides on the adequacy of the translation. The final strain is the *patient-oriented outcome* realized in the multicenter pilot studies,

where multi-level feedback from patients, psychosocial professionals, and interdisciplinary professionals regarding the content, design, feasibility, and efficacy of the tool are collected. The core of this QI project is a consensus-based multilevel approach characterized by iterative processes achieved by applying PDSA cycles in all steps of conceptualization and implementation of this project [18]. These cycles are continuously repeated to assure the adaptation of the tool to clinical practice including the perspectives of all stakeholders involved. In the following sections development and evaluation measures are described. All measures are applied repeatedly in this iterative development process. The study flow chart in ► **Fig. 1** gives an overview of all QI interventions.

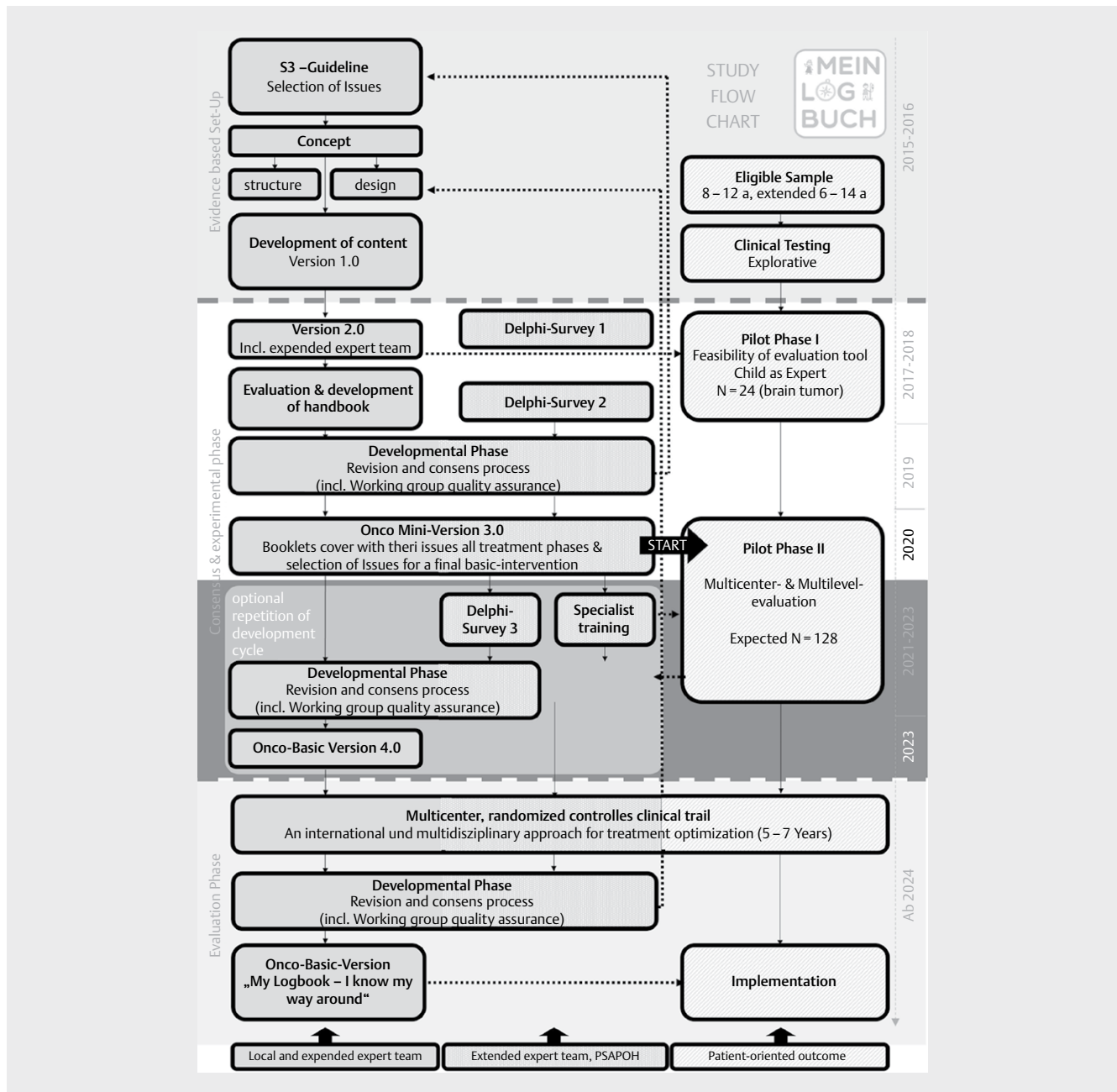
Consensus and evidence-based development

The *local expert team* uses their individual expertise in face-to-face discussions and telephone conferences to select critical disease-related issues for the “My Logbook”. All multidisciplinary experts, including specialists for the specific booklet topics, are invited either via a personal invitation because of their specific expertise in the field or an official announcement in a regular newsletter for psychosocial professionals. Hence, booklets including the key intervention elements are conceptualized and developed for the specific topics based on clinical and pediatric psychological considerations and by a multidisciplinary approach in regular meetings. Additionally, experts in specific topics such as pain were invited for the development of specific booklet themes. Furthermore, expert meetings are used for decisions on age-appropriate design and structure. Since the QI project is designed as a cyclical process, the planning phase is repeated after every evaluation step including data collection to integrate new findings directly in the updated versions.

The booklet drafts proposed by the expert team are hence disseminated to the *extended expert team* in an online delphi survey to gather multi-professional input and feedback regarding *content*, *method*, and *design*. The responses are coded as approval, minor or major revisions, or supplemental material. Consensus is defined as 80% of experts approving or suggesting minor revisions. Each delphi round is concluded by a final evaluation of the agreement to the standards by the *specialist group for quality assurance (PSAPOH)*. Further details on the proceedings and results of the delphi survey will be available in the corresponding brief report [32].

Multicenter pilot studies

The first version of the “My Logbook” is directed towards pediatric oncological patients from six to 14 years of age. Already during the conceptualization, single sections and methods were conducted in a clinical setting by the psychosocial staff in a first clinical testing phase at the local hospital. The patient and expert feedback gathered in this exploratory process was incorporated in the tool before starting the first pilot phase which aimed to gather the perspective of patients, practicing psychosocial, and interdisciplinary professionals regarding its design and feasibility in the clinical context to realize the goal of developing a practice-oriented tool. Furthermore, this patient-oriented testing follows the principles of public and patient involvement, including the children’s perspective in the design and development of the intervention [33].



► Fig. 1 Study-Flow-Chart of the QI Project “My Logbook – I know my way around”.

Although it is the aim of the “My Logbook” project to offer access to optimal standardized care to all patients treated in pediatric oncology and hematology, in – and exclusion criteria had to be defined for the first developmental phase of the booklets to determine a minimum standard during the consensus and experimental phase. The inclusion criteria are chosen to reflect the group with families/children at standard risk (suffering a higher degree of stress), according to the Pediatric Psychosocial Preventative Health Model (PPPHM) [34], defining the group as follows: children aged between 6 and 14, German language, with no mental or cognitive disabilities. Exclusion criteria encompassed: patients being too young or too old, or missing consent to the usage of their data for scientific purposes. Patients who could not be included in the study

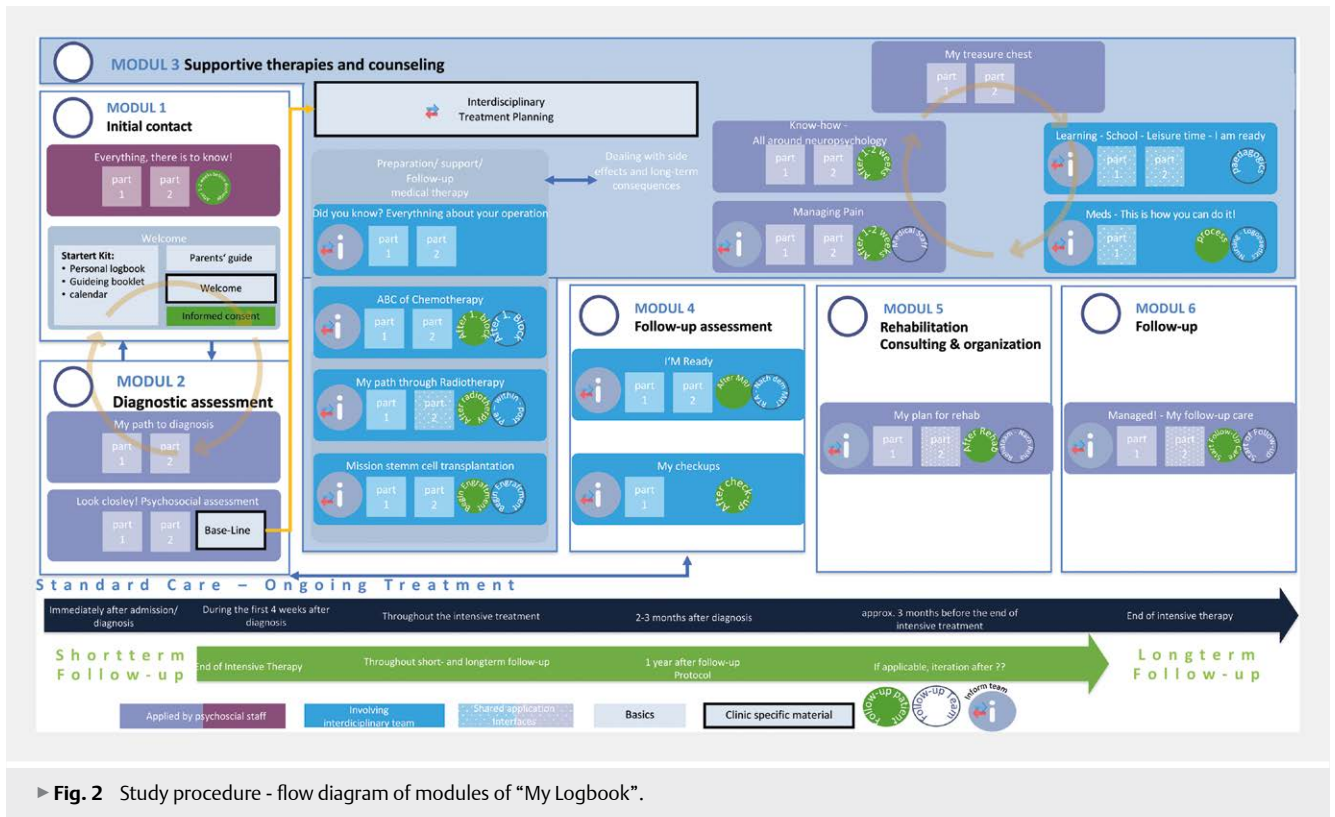
would nevertheless be provided with the materials of “My Logbook”.

During the clinical testing phase and the first pilot phase regular research meetings of the *local experts* were used to discuss the experiences and feedback of clinical psychologists and trainees at the head center and to adjust the evaluation forms in a self-learning process.

Details on the trial can be found in the clinical trial registry with the following ClinicalTrials.gov Identifier: NCT04474678.

Specialist training

All experts participating in the multi-center pilot study also receive specialist training in form of a four-hour workshop, followed by bi-



► Fig. 2 Study procedure - flow diagram of modules of "My Logbook".

monthly study coordination meetings to exchange experiences in the use of the tool, gather feedback on the current version, and discuss encountered issues. This training is intended to standardize the application of the "My Logbook" by capacitating all members to appropriately use and adapt the tool to the patients' individual needs. In addition, psychological contents and concepts of the respective topic areas are concretely recorded in the context of the booklets. Furthermore, there is a non-published manual with instructions for the implementation and interpretation of the results of the "My Logbook" which clearly references the updated S3-Guideline [1], and summarizes the underlying psychosocial processes as well as the complex activity within the framework of routine care [31].

Method "My Logbook – I know my way around"

The described developmental and evaluation process is meant to result in the „Onco-Basic-Version" of the "My Logbook" as a minimum standard for psychosocial care in pediatric oncology and hematology. It is planned to comprise a starter kit and 16 booklets which together should provide information on and interventions for the most relevant topics in psychosocial care in pediatric oncology to accompany the child from diagnosis to follow-up care (for a schematical overview see https://www.gpoh.de/sites/gpoh/kinderkrebsinfo/content/e1676/e176475/e176588/e260155/PsychosozialeBasisversorgung_MeinLogbuch_Oncobasicvers.2.0.1_2022-08-30_ger.pdf). Moreover, the method thus should standardize and improve, but not replace current clinical practice.

All booklets are divided into two face-to-face sessions, which always include a psychoeducational, a work and exercise part, and a reflection part. These are not fixed training sessions, but rather

an applied taking an individualized approach into account with the young patient. To ensure age-appropriacy every booklet should provide practical materials with enhanced stimulative elements to encourage the child to actively explore the topic. This should also allow the intervention to go beyond the mere provision of information by introducing the active implementation of treatment interventions [35]. Bringing the personal Logbook to each session with the psychosocial staff and if applicable with interdisciplinary staff team should enable the patients to document their individual treatment history in a process-oriented manner. Structural and organizational information should be provided to guide the patients and families through the therapy process and prepare them for the transition into aftercare. The underlying psychosocial expertise is decisive in the implementation. It is prerequisite that it is carried out by a psychosocial specialist who has received further training in this area (ensuring correct indication, adequate time frames, use of appropriate supplementary materials/methods, integration into the overall care network (crisis intervention, intensified care, etc.)) involves ongoing care actions within the standardized process.

As visualized in ► Fig. 2, the complex process is operationalized with 16 booklets which follow the module-based structure of the psychosocial process accompanying pediatric oncological diseases proposed by Leiss and Schröder et al. [1, 30].

Outcome measures

Baseline

In the initial interview and the first diagnostic session, sociodemographic, psychosocial, and medical data are assessed. Sociodemographic variables include age, sex, type of school, parental education, and mother tongue. Medical information encompasses medi-

cal diagnosis and treatment. For the psychosocial baseline, questionnaires on quality of life (KINDL-R) [36] and behavioral problems (SDQ) [37] are handed out to the patients and their parents. In addition, patients' health beliefs are assessed with an adapted questionnaire assessing the patients' health literacy ("Health Competence Scale", adapted from Grootenhuis & Last [38] and van der Zaag-Loonen et al. [39]). Evaluation of intelligence is optional and may be carried out using standardized IQ test procedures such as the Wechsler Intelligence Scale for Children (WISC-V) [40]. This selection of methods was a result of feedback from psychosocial staff and from patients collected in the first pilot phase during which methods were not fixed yet.

Process oriented screening

► **Fig. 2** visualizes the entire treatment process which can be accompanied psychosocially using the "My Logbook-Onco Basic version". Each of the 16 booklet is structured in a similar way. Though selecting the appropriate booklets for the patient might be overwhelming at first sight, the complexity of the "My Logbook" tool is necessary to depict and do justice to the complexity of psychosocial aspects accompanying pediatric oncological diseases and to document the individual process.

Level 1 – Patients

Since the integration of patients into the developmental process is a main goal of the project, an important intermediate step is the development of a process – and patient-oriented evaluation tool as described by Weiler-Wichtl et al. in 2021 [41]. The two-step evaluation is applied at the beginning and end of each of the two sessions as well as in an optional follow-up (if indicated by the S3-Guideline [1]). This tool aims to operationalize the regular psychosocial assessment in daily routine and hence encompasses two principal measures: *Emotional state* and the *expert scale* evaluating the subjective knowledge of the child regarding the specific disease-related booklet topic. Furthermore, it evaluates how much „My Logbook“ appealed to them. Following the rationale of a process-oriented screening these two variables are measured at the beginning and end of each session with the child. This has three main benefits: Firstly, it standardizes the typical structure of an intervention session, starting and ending it with the evaluation of emotions and knowledge. Secondly, the assessment of the current state allows the professional to adapt therapy planning to the patient's individual needs. Thirdly, the repeated assessment with the same standardized tool produces an individual patient-reported outcome for daily routine, facilitating the longitudinal comparison to evaluate changes over time, thereby serving as a criterion for the accomplishment of psychosocial goals. Furthermore, it overarches all issues and assessments from the diagnosis to follow-up care, thereby enabling the comparison between stakeholders as well as to a greater sample. Therefore, it allows for the longitudinal assessment of patients' information and well-being while also serving as a basis for the evaluation of the "My Logbook" as a whole [41]. Finally, the multiple usage of the tool meets ethical (patients are not overburdened by additional testing but receive tailor-made psychosocial interventions) and statistical or rather diagnostic considerations (limited assessment options of questionnaires).

Level 2 – Psychosocial evaluation

After each session with the child, the psychosocial experts register information on feasibility regarding the setting (inpatient or outpatient treatment, patient by itself or accompanied), their own profession, whether experts of other professions were involved (nursing or medical staff), duration of the intervention and covered themes as well as how well the administration worked and what they were missing. Additionally, the psychosocial experts rate the patient's knowledge on the same scale described above which can consequently be compared to the child's self-assessment as well as from the perspective of the interdisciplinary team; and they can indicate wishes, suggestions, and experiences.

Furthermore, each booklet includes the relevant psychosocial goals which the local expert team defined a priori in the initial developmental phase based on the S3-Guideline [1]. Hence, after each session, the psychosocial experts are asked to indicate whether the specific psychosocial goal was achieved or not. This serves as a basis for the deduction of appropriate follow-up interventions. Furthermore, there is an open response field for comments. All information gathered on the clinical feasibility is systematically recorded to allow for the analysis within a feasibility study as an evaluation of the tool.

Level 3 – Interdisciplinarity

As the integrated care system is a major principle of psychosocial care, interfaces to medical staff were also evaluated [13]. To this end two methods were considered: On one hand special sections in the booklets should encourage patients to use their booklets also during medical sessions (checklist for diagnostic or treatment consultation). This is registered by the psychosocial expert mentioned above. On the other hand, where applicable, medical staff is asked to assess the feasibility and quality of medical procedures by evaluating the patients' and carers' level of information as well as their confidence in handling the situation. As visualized in ► **Fig. 2**, evaluations in face-to-face discussion with the local medical team were scheduled at set time points based on the medical protocol (e. g., in the beginning, intermediate, and end of radiotherapy).

Statistical Analysis

Data will be analyzed with the statistical programming environment R, applying a combination of descriptive and inferential statistics. For probabilities a significance level of $\alpha = .05$ will be used and where possible, effect sizes will be computed. To analyze the change in the patients' level of expertise and the type of emotion over time, generalized linear mixed-models with Poisson distribution and log link function will be used due to their aptness for non-independent categorical data [42]. Each model will predict the progress of (positive, neutral, or negative) emotions over time based on three to five points of measurement, depending on the booklet.

Discussion

The present project represents a novel approach of directly translating theoretical quality standards for psychosocial care into daily clinical practice. The consistent interaction between local experts, the expanded expert team, and patient-reported outcomes dur-

ing the development, provides the basis for integrating various perspectives, needs, and regional differences into one unifying tool for high-quality patient-centered, evidence – and consensus-based care. Thereby the constant supervision and repeated delphi evaluation by the extended expert team and especially the PSAPOH (the authors of the standards used for the translation) aims to ensure that the tool represents significant step for the implementation of the standards of care, adequately depicting all key principles of the S3-Guideline [1]. Within the multi-centered pilot study, the adequacy of the translation within the clinical setting is also evaluated by the patients and professionals, bridging the gap between evidence-based standards and clinical practice and ensuring that the patients are actively involved in the developmental process. On the one hand, the pilot study aims to reinforce the standards and guidelines in clinical practice by engaging professionals, thereby facilitating decisions on adequate interventions and therapy goals. On the other hand, the study evaluates whether “My Logbook” effectively informs the patients to understand their own needs and rights, thereby empowering them to voice their demands. Since the patient-centered outcome is the core of the “My Logbook” project, further development of the tool will strive to include the patient perspective even more thoroughly into the design and development.

It can be considered the first tool to allow for the continuous psychosocial accompaniment and monitoring of patients throughout the entire process of pediatric oncological and hematological treatment. It thereby safeguards that all patients receive all the necessary support in their individual situation as well as all relevant information including the ability to use it [35], while also providing health care professionals with the appropriate tools and interventions to give the necessary support. Considering Kazak et al. 's *Integrative Model of Pediatric Medical Traumatic Stress*, this structure should ensure that all patients receive a certain baseline support that includes psychoeducation and is not limited to crisis intervention [43]. Owing to the complexity of psychosocial care and the manifold biopsychosocial influences differentiating between patient, the tool, its development, and implementation also gain considerable complexity. Although this might be a point of critique, the high number of booklets and the thorough differentiation between the stages of the treatment process are necessary to allow for patient-centered care that is adapted to each patient's individual situation, history, and needs. However, it is important to note that one tool can never encompass all the existing interventions and that the “My Logbook” hence does not aim to substitute but rather to structure and complement the existing care. Hence, it should not be misread as a tool that can be directly given to the patient without supervision, which would lead to a reduction in quality of care. Future work will need to further evaluate and develop the tool, and take measures towards its implementation including expert trainings, workshops, and decision trees to ensure the adequate while also individually flexible application of the “My Logbook” as well as awareness for the relevance of scientific research among clinical professionals. Moreover, the overall conditions for psychosocial research need improvement whereby study nurses in each center included in the study would help to ensure

comparability and facilitate coordination of and communication about the project.

One major distinguishing feature of the “My Logbook” methodology is the patient-oriented evaluation in a multi-center pilot study as the final step towards linking standards and practice. Thereby the iterative evaluation of the applicability, and efficacy of the tool by the patients, the psychosocial professionals, and the interdisciplinary team allows for the integration of the different perspectives into the design of the tool. Furthermore, this iterative evaluation approach allows for the systematic recording persistent gaps between evidence-based standards and clinical practice as well as regional differences and interdisciplinary discrepancies. Through the consequential analysis of these factors, potential reasons for deficient communication and low feasibility (eg., duration, interdisciplinarity) can be identified and preventative measures to improve applicability and communication might be derived. This continuous systematic evaluation of the tool regarding its feasibility, including the patients' knowledge and emotional state, has potential to be the first psychosocial tool to serve as basis of a multi-centered psychosocial therapy optimization study. The exploratory results of the multi-centered pilot study will shed light on the feasibility of the “My Logbook”. Further pilot studies with larger sample size will be necessary to evaluate the operationalization of feasibility, increase the inclusion of the patient perspective, and assess the influence of environmental factors, before a randomized controlled trial to evaluate validity and reliability of the “My Logbook” can be planned. Based on such studies, directly connecting evidence-based standards and clinical practice in terms of therapy optimization, compulsory regulations for psychosocial care in pediatric oncology and hematology could be derived, ensuring the necessary resources are available in all clinics to provide every single patient with the individualized care they need.

Contributor's Statement

L. Weiler-Wichtl, A. Kollmann, V. Fohn-Erhold, and U. Leiss conceptualized and designed the project. L. Weiler-Wichtl and U. Leiss acquired funding. L. Weiler-Wichtl, V. Fohn-Erhold, C. Schneider, A. Schwarzingler, K. Krottendorfer, T. Pletschko, J. Gojo, A. Peyrl, K. Dieckmann, A. Kollmann, I. Slavic, Verena Rosenmayr and U. Leiss acted as part of the local expert team, thereby contributing to the conceptualization, design, evaluation, development, and implementation of the tool. J. Fries, V. Fohn-Erhold, and M. Hopfgartner were involved in the acquisition analysis and interpretation of the project the protocol describes. R. Hansl contributed to editing the manuscript. All authors read and approved the final manuscript and agreed to be accountable for their contributions.

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Conflict of Interest

The authors declare that they have no conflict of interest.

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