

Development of a tool for palliative care needs assessment and intervention: mixed methods research at a Swiss tertiary oncology clinic

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Background: Palliative care interventions improve quality-of-life for advanced cancer patients and their caregivers. The frequency and quality of service provision could be improved by a clinical tool that helps oncology professionals to assess unmet needs for palliative care interventions and to structure the interventions delivered. This paper aims to answer the following research question: what do oncology professionals and cancer patients view as important elements in a clinical tool for assessing unmet palliative care needs? Based on the feedback from professionals and patients, we developed and refined an intervention-focused clinical tool for use in cancer care.

Methods: This study used a prospective convergent mixed methods design and was carried out at a single tertiary hospital in Switzerland. Healthcare professionals participated in focus groups (n=29) and a Delphi survey (n=73). Patients receiving palliative care were interviewed (n=17). Purposive sampling was used to achieve maximal variation in participant response. Inductive content analysis and descriptive statistics were used to analyze focus group discussions, open-ended survey questions and interview data. Descriptive statistics were used for analyzing quantitative survey items and interviewee characteristics.

Results: Focus groups and Delphi surveys showed that seven key palliative care interventions were important to oncology professionals. They also valued a tool that could be used by doctors, nurses, or other professionals. Participants did not agree about the best timepoint for assessment. Two versions of a pilot clinical tool were tested in patient interviews. Interviews highlighted the divergent patient needs that must be accommodated in clinical practice. Patients provided confirmation that a clinical tool would be helpful to them.

Conclusions: This paper reports on research carried out to understand what elements are most important in a tool that helps oncology professionals to identify patients' unmet needs and provide tailored palliative care interventions. This study demonstrated that professionals and patients alike are interested in a clinical tool. Responses from oncology healthcare professionals helped to identify relevant palliative care interventions, and patients provided constructive input used in designing a tool for use in clinical interactions.

Keywords: Palliative care; medical oncology; needs assessment

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Introduction

Evidence is increasing about the positive effects of specialized palliative care for cancer patients. Specialized palliative care consists of definable palliative care interventions (1-5), which can be distilled to seven dimensions (6-12): illness understanding, symptom management, decision support, professional networks, family support, end-of-life preparation, and spiritual issues. A common approach is to compare the difference between the outcomes of additional specialized palliative care services compared to the outcomes of standard treatments (13). Although the evidence for palliative care is increasingly clear, questions arise regarding when to refer patients for specialized palliative care and who should deliver key palliative care interventions. Experts have proposed referral criteria for specialized palliative care (14) based on a prior systematic review (15). Possible clinical triggers for referral have also been proposed (16). Early integrated palliative care is delivered both by palliative care specialists and by oncology professionals. The effectiveness of early integrated specialist palliative care has been proven (17), with beneficial effects on patients' and families' quality-of-life (18).

Palliative care interventions encompass various services (e.g., education, counselling, coordination, medication, procedures), thus requiring broad professional skills. By helping practitioners to identify patients' palliative care needs, patient outcomes may be improved (19). Yet some oncology practitioners struggle with systematically assessing palliative issues as a part of routine care (20).

According to Wiles *et al.*, a clinical tool is defined as an aid in translating a clinical standard into everyday practice (21). A clinical tool provides an auditable structure for clinicians to implement improvements to patient care, and it should be integrated into workflows and patient records (21). A clinical tool can give professionals a helpful framework for their clinical interactions, and it can give guidance to oncologists about when a referral to specialist palliative care is indicated. Our research team conducted a literature review of validated tools in use in palliative care (22), building upon the work of Carlson *et al.* (23) and Moghaddam *et al.* (24). Seventeen articles were reviewed in depth to identify a clinical tool that can screen for multidimensional unmet needs in palliative care patients. The review found no tools that matched the designated criteria (22).

Considering this, our research group set out to answer the following question: what do oncology professionals and cancer patients view as important elements in a clinical tool for assessing unmet palliative care needs? Based on the results, we developed a tool that can help the non-specialist to identify and track unmet palliative care needs. This paper presents an intervention-focused clinical tool for assessing unmet needs in seven domains relevant to cancer care. We present the following article in accordance with the SRQR and CREDES reporting checklists (available at <https://apm.amegroups.com/article/view/10.21037/apm-22-994/rc>).

Methods

Context

This research was carried out at a tertiary hospital serving St. Gallen and the surrounding region of Switzerland. A convergent mixed methods design was used to collect and analyze qualitative and quantitative data (25). The iterative approach was carried out in two stages.

Highlight box

Key findings

- This study demonstrates that oncology healthcare professionals and cancer patients alike are interested in a clinical tool to track patients' unmet needs for palliative care and the interventions delivered to address the identified needs.

What is known and what is new?

- A clinical practice tool can help healthcare professionals to systematically assess multi-dimensional palliative care needs;
- This study triangulates opinion from multiple stakeholders involved in palliative cancer care;
- A new tool was developed to detect and document patients' unmet needs and the steps taken to alleviate needs.

What is the implication, and what should change now?

- Rigorous validation should be carried out on the newly developed tool, then implementation research should be conducted to evaluate the feasibility of including the tool in everyday clinical practice.

Stage 1: research with oncology professionals using focus groups and Delphi survey

Focus groups with oncology professionals explored the assessment, documentation, and provision of defined palliative care interventions. Inductive content analysis was used and amended by open codes and sub-codes (26). Purposive sampling was used to recruit participants from a range of professional backgrounds. The strategy of maximal variation sampling was used to ensure that participants represented heterogeneous points-of-view (27). After each focus group, researchers discussed new concepts, reached consensus, and adapted the discussion guide (28). Open inductive coding and category assignment defined the domains used in content analysis. The focus group guide can be found in Appendix 1 (available at <https://cdn.amegroups.cn/static/public/apm-22-994-1.pdf>). After the third focus group, no new codes emerged. Thus, it was determined that code saturation had been reached (29).

To systematically assess the views expressed in the focus groups, statements were prepared for an anonymous Delphi survey. Two survey rounds were planned from the outset (30). The statements presented to the expert panel were reviewed to reduce bias. These statements were presented to participating healthcare providers, recruited by purposive maximal variation sampling directed at obtaining varied perspectives (27). Respondents rated the statements from “*I strongly disagree*” [1] to “*I strongly agree*” [6]. High levels of consensus were sought, operationalized as items that had a mean ≥ 5 and median ≥ 5 . Statements that achieved high consensus for agreement were considered essential elements in the clinical tool. Survey Monkey was used to administer the Delphi survey. The first round was sent to 28 individuals. The second round of the Delphi survey presented revised statements to all oncology healthcare professionals in the hospital (approx. 100 individuals). As the second Delphi round results largely confirmed the results of the first round, no further Delphi rounds were planned (30). The Delphi survey statements can be seen in Appendix 2 (available at <https://cdn.amegroups.cn/static/public/apm-22-994-2.pdf>).

Stage 2: patient interviews

Patient interviews were conducted to understand what is important to patients in a clinical tool. The first set of interviews were based on an amended version of the European Society for Medical Oncology (ESMO) booklet, *A Guide for Patients with Advanced Cancer* (31,32). Interviews focused on the topics of clinical usefulness,

comprehension, and acceptability. Based on these interviews, a new version of the clinical tool was drafted. This tool was tested with interviews of another five patients. Inductive content analysis was used to analyze interview data.

Inclusion criteria for the patients eligible for interview were: stage IV cancer disease, ≥ 18 years old, Eastern Cooperative Oncology Group (ECOG) Performance Status 1–3 (33), a positive answer to the statement: “*the treating healthcare professional wouldn't be surprised if the patient would die within the next 12 months*”, and without cognitive or psychiatric impairment. Purposeful sampling according to the maximal variation strategy (27) was used to include patients with heterogeneous experiences of palliative care (male and female patients from a range of ages and socio-economic backgrounds with different diagnoses and illness trajectories). Sample size was determined by data saturation. The interview guide is presented in Appendix 3 (available at <https://cdn.amegroups.cn/static/public/apm-22-994-3.pdf>).

Data management and analysis

Data were stored digitally using password protection and encryption to ensure responsible handling of sensitive personal data. Focus groups were analyzed using MAXQDA Version 5, and patient interviews were analyzed using ATLAS.ti Version 7. Data saturation was used as the guiding principle for sample size determination of the focus groups and interviews. The threshold for consensus from the Delphi survey was set *a priori*, and two rounds of the survey were planned prior to the survey's commencement.

Statistical analysis

Descriptive statistical analysis was conducted using StataIC 12. Descriptive statistics were carried out to better understand the professional and patient groups who participated in the research. As no parametric statistics were used, power calculations were not used in sample size determination.

Ethics approval and consent to participate

All research activities were granted approval by the Ethics Commission of Eastern Switzerland (*Ethikkommission Ostschweiz*) under project number BASEC 2016-01561/EKSG 15/039. All participants provided written informed consent. Research was carried out in accordance with the regulations of the Ethics Commission of Eastern Switzerland

and the Declaration of Helsinki (as revised in 2013).

Results

Focus groups

Three focus groups of 90–120 minutes were conducted with 29 participants in total: 20 physicians, eight nurses, and one psychologist. Of these professionals, 15 were oncology specialists, five specialized in palliative care, five were dual specialists in oncology and palliative care, and four were internists/generalists. Professionals worked in both outpatient and inpatient settings. Discussions centered on the components of a clinical tool for palliative care interventions, considering the following questions:

- ❖ What topics should be assessed?
- ❖ How do health care professionals assess palliative needs and provide palliative care interventions?
- ❖ Who assess and provides for palliative care needs? What are the roles of different health care professionals?
- ❖ When in the advanced cancer disease trajectory should palliative needs assessment occur?

All clinicians participating in the focus groups agreed that the seven following domains of palliative care interventions are important:

- (I) Illness understanding;
- (II) Symptom management (including pain, fatigue, drowsiness, nausea, breathlessness, anorexia, anxiety, and depression);
- (III) Decision support;
- (IV) Professional networks;
- (V) Family support;
- (VI) End-of-life preparation, and
- (VII) Spiritual issues.

Focus group discussions highlighted the challenges for oncology physicians and nurses to efficiently document the palliative care interventions they provide. Participants said that detecting and assessing needs, then delivering and documenting key palliative care interventions requires specific skills, especially awareness of the vulnerability of patients and their caregivers. Clinicians must also notice subtleties of patient communication. Focus groups also discussed how the attitudes of healthcare professionals lead to individual differences in how clinicians provide palliative care interventions. Participants agreed that it is important that the psychological symptoms of patients are systematically recorded and monitored. Likewise, oncology

healthcare professionals said they need a reliable way to know how a patient understands his or her disease. Illness understanding includes the hopes and fears of patients and assesses patients' capacity to make decisions regarding cancer therapy and the end of life. A possible mental overload of patients must be respected. Except for spiritual needs, clinicians said that it was a professional responsibility to address each of the seven domains of palliative care interventions.

Focus group participants said that key palliative care interventions may be assessed and documented by one individual healthcare professional or by several healthcare professionals—either sequentially or jointly. A tool should not be specifically developed for one professional group to use exclusively. Participants discussed triggers that influence the assessment and monitoring of key palliative care interventions, such as setting (e.g., emergency department, outpatient consultation, palliative care unit, or acute care ward) and disease progression or complications.

The analysis of focus group discussions led directly to the development of the statements used in the Delphi survey, which was the next step in this research project.

Delphi survey

Statements derived from focus group results were rated by participants in two rounds. Twenty-three individuals (16 physicians, four nurses, one psychologist, and two other professions) responded to the first survey. In the second round, a total of 50 people responded: 37 oncologists, six specialist palliative care/oncology nurses, and seven other professionals. Statements about the following topics were evaluated:

- ❖ Seven statements on which palliative care interventions are important;
- ❖ Four statements on how key palliative care interventions are provided and documented;
- ❖ Eight statements on who assesses, provides, and records palliative care interventions;
- ❖ Twelve statements on triggers (setting and disease trajectory) for delivering key palliative care interventions.

All the seven key palliative care interventions listed were rated as important in the clinical care of patients with advanced cancer. Respondents believed that both oncologists and oncological nurses can provide appropriate interventions themselves or refer to appropriate specialists. Oncologists and oncological nurses are both qualified to

assess of all seven domains of palliative care interventions. No consensus was found for the statements concerning at which point(s) in the disease trajectory palliative care interventions should be evaluated and provided.

In the first round of the Delphi survey, consensus was reached about what should be assessed in a clinical tool, how the assessment should be carried out, and who could make use of a clinical tool. No consensus was reached about when a clinical tool should be used. With similar results, the second round of the Delphi survey confirmed the results of the first round. The Delphi surveys brought clarity concerning which palliative needs should be assessed, how the delivery of interventions could occur, and the healthcare professionals who should carry out these activities. No consensus was found about the best timing for delivering key palliative care interventions. The Delphi survey findings were elaborated upon through patient interviews.

Interviews with patients

The ESMO booklet, *A Guide for Patients with Advanced Cancer*, introduces patients with advanced incurable cancer to palliative care issues (31,32). The booklet was determined to be a useful basis on which to build a clinical tool. The ESMO booklet was adapted to produce a tool with the following characteristics: uses a structured format, covers the seven domains of palliative care interventions, detects unmet needs, and provides a direct link to actions that healthcare professionals can take to provide interventions. Interviews with patients (n=12) were conducted to assess the adapted booklet.

Patient interviews confirmed that all seven palliative care domains should be addressed. End-of-life preparation and spiritual issues were particularly compelling to most participants, but some patients did not want to discuss their spiritual needs with their healthcare team. The adapted booklet helped some patients to understand that they could get help from healthcare professionals for topics they had assumed to be personal. For example, the booklet helped one patient to realize that her husband could also receive advice and support for the challenges of caregiving and for his anticipatory grief.

Participating patients felt that the topics and questions in the tool were relevant and necessary. However, they found the volume of information, layout, and design of the ESMO Guide to be unsuitable for use in a clinical interaction. The guide demonstrated to patients that healthcare providers care about their palliative needs.

“Broaching these topics shows me that I can contribute and that the hospital and the team here cares.”—Patient 12.

Some patients saw themselves in an active role, expressing a desire to engage with palliative care topics, think about existential issues, and prepare for medical consultations in advance.

“[Certain topics] were for me personally very interesting. Taking time for memories, for family, for my will. These are topics that I personally find very important.”—Patient 8.

Patients also expected their oncologist to take the initiative in discussions about palliative care.

The interviewees had a range of opinions about when the ESMO Guide should be given to patients. The following comments illustrate the diversity of patients' views regarding the appropriate point in time for discussing palliative care topics:

- ❖ *“Not at the beginning. I, for example, needed 2-3 months after my diagnosis before I could become interested in these topics.”—Patient 10;*
- ❖ *“At the beginning of treatment”—Patient 2;*
- ❖ *“When treatment stops progressing. The treating doctor should decide.”—Patient 8.*

These comments illustrate the divergent needs that must be accommodated in clinical practice.

The results of the first round of interviews made it clear that a clinical tool should be structured differently than the ESMO booklet. Thus, the contents of the ESMO booklet were revised into a new version of a clinical tool. The new format simplified and restructured the patient booklet to create a tool designed to be used during a clinical interaction. The symptom and needs assessment pages of the tool are shown in *Figures 1,2*. The full clinical practice tool is available in Appendix 4 (available at <https://cdn.amegroups.cn/static/public/apm-22-994-4.pdf>).

The revised tool was tested in five interviews with patients. *Table 1* provides descriptive statistics of both interview phases.

Patients gave positive feedback about the revised tool.

“I think it is very good to talk about these things.”—Patient 15.

Participants felt that the tool addressed issues important to them.

“It is good to know about this information in advance, for example, weight loss... It would be good know, for example, before starting chemotherapy. It's important to know about what is offered, treatment options, early on.”—Patient 17.

Interviewees found the text and needs assessment questions easy to understand and saw the pilot clinical tool as useful for being integrated into the care process. Patients

Assessment of symptom levels and questions about the need for support

Patient sticker

Date: _____

Assessment	Palliative interventions	Completed	Delegated	Completed	Delegated	Completed	Delegated
<p>1. First, estimate the intensity of the symptom in the last 24 hours on a scale from 0 to 10 (0= none to 10= worst possible).</p> <p>2. Then consider whether you have a need for support from an oncological professional.</p>	<p><i>Legend for abbreviations:</i></p> <p>O= Oncologist PO= Psycho-oncologist SPO= Supp./Pa. Oncologist D= Dietician ON= Oncology nurse PT= Physical Therapy Z= Other</p>						
<p>Pain</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Fatigue (lack of energy)</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Nausea</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Loss of appetite</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Anxiety (inner unrest/nervousness)</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Depression (feelings of sadness)</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Breathlessness</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Drowsiness (dizziness/sleepiness)</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Other symptoms</p> <p>0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support?</p> <p><input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Notes</p>	<p>Further measures to be taken</p>						

Figure 1 Symptom assessment.

Needs, demands, and supports while living with cancer

Assessment	Palliative interventions	Completed	Delegated	Completed	Delegated	Completed	Delegated
<p>1. First, estimate the intensity of the symptom in the last 24 hours on a scale from 0 to 10 (0= none to 10= worst possible).</p> <p>2. Then consider whether you have a need for support from an oncological professional.</p>	<p><i>Legend for abbreviations:</i></p> <p>O= Oncologist PO= Psycho-oncologist SPO= Supp./Pa. Oncologist D= Dietician ON= Oncology nurse PT= Physical Therapy Z= Other</p>						
<p>Illness and illness progression Are you dealing with questions about your illness and its progression? 0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support? <input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Decision-making about cancer therapy Are you dealing with questions about how you will tolerate treatment, the goals of treatment, or the effect of treatment? 0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support? <input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Support at home and creating a care network Are you dealing with questions about your support at home, for example when you experience [physical] symptoms or if your condition worsens at home? 0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support? <input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Support for your family Is your family currently struggling with the situation and needs professional support or advice? 0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support? <input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Preparing for the end of life Have you given thought to how you want to be treated at the end of your life and are you dealing with questions such as living will, power of attorney, will, legacy, reconciliation.etc.? 0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support? <input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Spirituality Are you dealing with questions of spirituality, such as belief, religion, reasons for living, hope, hopelessness, etc.? 0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support? <input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Other issues: Which other issues are you dealing with? 0 1 2 3 4 5 6 7 8 9 10</p>	Notes:						
<p>Need for support? <input type="checkbox"/> no <input type="checkbox"/> no problem in this area <input type="checkbox"/> already receive support <input type="checkbox"/> yes <input type="checkbox"/> low <input type="checkbox"/> medium <input type="checkbox"/> high</p>							
<p>Notes</p>	<p>Further measures to be taken</p>						

Figure 2 Needs assessment.

Table 1 Profile and demographics of interviewees

Variables	Tool version 1	Tool version 2	Total
Interviews, n	12	5	17
Mean age (years)	69	63	67
Male gender, % [n]	75 [9]	80 [4]	76 [13]
Solid cancer diagnosis, % [n]			
Lung cancer	25 [3]	0 [0]	18 [3]
Gastrointestinal cancer	33 [4]	40 [2]	35 [6]
Urogenital cancer	8 [1]	20 [1]	12 [2]
Head and neck cancer	33 [4]	20 [1]	29 [5]
Other	0	20 [1]	6 [1]
Performance status (ECOG: 1–3), % [n]			
1, Restricted in physically strenuous activity	58 [7]	20 [1]	47 [8]
2, Ambulatory and capable of all self-care	33 [4]	60 [3]	41 [7]
3, Capable of only limited self-care	8 [1]	0 [0]	6 [1]
Missing data, n	0	1	1

ECOG, Eastern Cooperative Oncology Group.

suggested adding questions like: “*What makes you happy?*” or “*What gives you strength in everyday life?*”. Patients added that the oncologist should assess symptoms (e.g., anxiety and depression), as this is too difficult for patients.

Patients recognized that being confronted with palliative care topics may be stressful for some patients rather than supportive. Particularly, interviewees mentioned that some patients might avoid a discussion if they have not yet accepted that their illness is incurable. Interview participants highlighted that the outcome of a conversation about palliative care topics is dependent on the relationship between the patient and the healthcare professional.

“*A discussion about these topics stands or falls on the quality of the relationship with the doctor.*”—Patient 16.

Interview results showed that patients think that oncologists should take the initiative in assessing palliative care interventions. Patients desired guidance from a physician on these issues. Interviewees reported that without a tool, they tended to underestimate the possibility of addressing important topics. Patients found that a structured document would help to identify needs and address problems sooner. Early provision of information is very important. For example, patients approved of offering resources for symptom management even before a symptom occurs. Individual patients differed in their opinion on

optimal timing for delivering this information.

Discussion

This study demonstrates that both oncology healthcare professionals and patients near the end of life are in favor of structured support for integrating palliative care interventions into everyday clinical work. The results of this research highlight the importance of simple and well-defined needs assessment. Both professionals and patients share a commitment to monitoring palliative care needs and the interventions delivered to address patients’ problems.

According to a literature review this research group conducted the topic, other tools in use with the palliative care patient population do not offer features that are completely comparable to our newly developed tool (22). In comparison with other tools, the tool developed through this research is unique in the following ways. Firstly, this tool focuses on assessing unmet needs (34). Several tools that are currently in use, such as the Sheffield Profile for Assessment and Referral for Care (SPARC) (35), assess the presence of a need rather than an unmet need. Thus, wasteful measures may be put in place to address a need for which the patient does not wish for help or for which interventions have already been initiated to address the

need, yet the problem remains partially or fully unresolved. Secondly, the tool developed in this work is completed collaboratively with patients and healthcare providers, whereas most other tools, such as the Supportive Care Needs Survey-Short Form 34 (SCNS-34) (36) or the Needs Assessment Tool-Cancer (NAT-C) (37) rely on a single source (either patient report only or healthcare providers' perception of patient needs only). Interaction between patients and healthcare providers is an ideal approach for uncovering the full array of unmet needs experienced by a patient. Thirdly, the tool developed through this research includes seven dimensions of palliative care interventions. Many other tools address only a limited number of needs. Such approaches often emphasize patients' physical needs to the exclusion of social and spiritual needs, which are strong contributors to total pain (38).

Implementing this tool could improve the palliative care provided to patients. In this study patients and professionals considered seven dimensions of palliative care to be relevant in advanced cancer care from diagnosis to death. Monitoring palliative care needs on a regular basis would help to embed needs assessment into routine workflows. Interventions delivered by healthcare professionals should remain individualized to each patient's unique circumstances. Our study supports the centrality of healthcare providers using highly developed communication skills to determine the appropriate timing for initiating palliative care discussions. The clinical tool developed in this study was informed by professionals' and patients' perspectives on what is important in a clinical tool for assessing unmet palliative care needs among cancer patients.

Limitations

This study was conducted at a single site, which means that caution should be used in generalizing the results to other settings. The research unfolded somewhat organically over time. The scope of the research remained broad as the project progressed, such that important aspects of implementation were not explored adequately. In retrospect, the research could have been refined by formulating more specific questions to reach more precise conclusions. This could have allowed us to gain more insights into how a clinical tool could be implemented. For example, the project would have benefitted from more defined parameters regarding the audience for whom the tool is intended and the suggested time-point of assessment.

The phases of the study were not mapped out in advance.

Rather, the answers to initial questions prompted more questions, and the research plan was expanded to explore the emerging topics. After each step, the researchers engaged in reflection about what had been learned and what the next steps could be. As a result, the study was not structured to include rigorous validation procedures. Prospective validation of the tool has not yet been conducted. While these limitations impact the generalizability of the results, the findings can still provide insights that can be used in future research.

Conclusions

This study offers input from patients and practitioners about the aspects of a clinical tool that are important for palliative care needs assessment and interventions. This study clarifies which domains should be included in a clinical practice tool for palliative care interventions. It provides support for the claim that such a resource could enhance patient care. The pilot clinical tool developed in this study can facilitate the integration of palliative care into ongoing medical treatment.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the regional ethics board, the Ethics Commission of Eastern Switzerland (*Ethikkommission Ostschweiz*) under project number BASEC 2016-01561/EKSG 15/039. Informed consent was taken from all individual participants.

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