

ORIGINAL RESEARCH

Towards a novel approach guiding the decision-making process for anticancer treatment in patients with advanced cancer: framework for systemic anticancer treatment with palliative intent

K. Ribi^{1*†}, N. Kalbermatten^{2†}, M. Eicher³ & F. Strasser^{4,5}

¹International Breast Cancer Study Group, Coordinating Center, Quality of Life Office, Bern; ²Clinic Medical Oncology and Hematology, Department Internal Medicine, Cantonal Hospital, St. Gallen; ³Institute of Higher Education and Research in Health Care, Faculty of Biology and Medicine, University Hospital Lausanne, University of Lausanne, Lausanne; ⁴Cancer Fatigue Clinic at Onkologie Schaffhausen, Schaffhausen and Center Integrative Medicine, Cantonal Hospital St. Gallen, St. Gallen; ⁵Center Integrative Medicine, Department Internal Medicine, Cantonal Hospital St. Gallen, St. Gallen, Switzerland



Available online 18 May 2022

Background: Weighing risks and benefits is currently the primary criterion for decisions regarding systemic anticancer treatment (SACT) in far advanced cancer patients, also in the modern immunotherapy- and molecular-targeted driven oncology. Decision aids rarely include substantially key concepts of early integrated palliative care (PC) and communication science. We compiled decisional factors (DFs) important for guiding the use of SACT with palliative intent (SACT-PI) and explored these DFs regarding their applicability in routine clinical care.

Patients and methods: Clinician (participants: $n = 28$) and patient ($n = 15$) focus groups were conducted in an integrated oncology and PC setting. Thematic analysis was used to identify DFs. A Delphi survey of clinicians ranked the importance of DFs in routine decision-making. DFs were aligned with elements of the typical decision-making process, resulting in an eight-step guide for making SACT-PI decisions in clinical practice.

Results: Eight focus groups revealed 55 DFs relating to established topics like providing information and risk–benefit analysis, as well as to PC topics like patients’ attitudes, beliefs, and hopes; patient–physician interaction; and physician attitudes. Agreement on the relative importance was reached for 34 (62%) of 55 DFs, assigned to five elements: patient/family, clinicians/system, patient-clinician-interaction, information/patient education, risk–benefit weighting/actual decision. These themes are embedded in a potential clinically useful SACT-PI Decision Framework, which includes eight steps: assess, educate, verify, reflect, discuss, weigh, pause, and decide.

Conclusions: The SACT-PI Decision Framework integrates subjective patient factors, interpersonal factors, and PC issues into decision-making. Our findings complement existing decision aids and prompt lists by framing DFs in the context of SACT-PI and enforce the decision ‘process’, not the decision act. Further research is needed to explore the relative importance of DFs in specific patient situations and test structured decision-making processes, such as our SACT-PI Decision Framework, against standard care.

Key words: decision-making, communication, palliative oncology, interprofessional, physician attitudes

INTRODUCTION

Oncologists’ typically base treatment recommendations on survival, tumor control, and toxicity data from high-quality clinical trials.¹ In patients with resistant tumors and in unfit patients, anticancer treatment is often applied, even without sufficient supporting evidence. Many patients may

face toxicity with modest benefit from such treatments,² whereas in others a systemic anticancer treatment with palliative intent (SACT-PI) may alleviate cancer-related symptoms.^{3,4}

In modern oncology, patients with advanced disease often face uncertainty,⁵ and may have inaccurate perceptions of their prognosis^{6,7} and treatment goals.⁸ Moreover, they may have difficulties weighing the toxicity risk against potential benefits in terms of symptom control and quality of life.⁹ These factors can compromise informed decision-making and may contribute to so-called aggressive end-of-life care.¹⁰ An individualized decision process¹¹ becomes increasingly important to address palliative care (PC) domains like multidimensional symptom burden, illness and

*Correspondence to: Dr Karin Ribi, International Breast Cancer Study Group, Effingerstrasse 40, 3008 Bern, Switzerland. Tel: +41-511-94-00; Fax: +41-389-93-92

E-mail: karin.ribi@ibcsg.org (K. Ribi).

†These authors contributed equally as co-first authors.

2059-7029/© 2022 The Authors. Published by Elsevier Ltd on behalf of European Society for Medical Oncology. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

prognosis understanding¹², spirituality,¹³ life closure,¹⁴ or family involvement.¹⁵ Current evidence suggests that non-medical factors like attitudes, values and beliefs, socio-demographic variables such as (young) age and aspects of physician–patient relationship may influence SACT decisions.¹⁶ Current evidence to guide oncologists' decision making for or against SACT-PI is rare.^{17,18}

Decision support is a core component of early PC.^{17,19,20} Randomized, controlled trials of early specialized PC demonstrate improved quality of life for both patients and family members.^{21–23} In these trials, modified, less invasive palliative chemotherapy regimens were applied, resulting often in better quality of life and similar or even prolonged survival compared with standard regimens. Oncologists or other clinicians, supported by specialist PC clinicians, can deliver palliative interventions.^{24,25} Tools to improve oncologists' alertness of symptoms^{26,27} are reported to be effective for symptom management performance, whereas communication skills training improves communication, but not quality of decision.²⁸ Existing decision aids (DAs) for advanced cancer patients are usually designed for specific cancer types, with a few being not disease-specific.^{29–31} They provide information on prognosis, treatment options including supportive care and adverse events. DAs apply rating scales to the possible harms and benefits of each option, elucidating patients' preferences and include measures for value clarification.³² Such an approach, however, may not adequately touch upon essential subjective aspects, values, and burdens that are relevant when facing an advanced incurable illness and its treatments.^{13,33} In current DAs, such domains are infrequently covered, and if so, they are in a format similar to a prompt list.³¹

Decision making is characterized as a process³⁴ rather than a singular event, including information giving, eliciting patients' values and preferences, weighing risks against benefits, and the actual decision.^{8,12,35} Reflecting personal values and knowledge about the natural course of the disease are essential to prepare for the decision-making encounter.^{36,37} Various clinicians [i.e. oncologists, general practitioners (GPs), nurses] typically involved in the care of patients also play an important role when patients face end-of-life decisions.^{38,39} Since current DAs in advanced incurable cancer do not incorporate non-medical factors and essential palliative domains in the decision process, we aimed to identify and characterize decisional factors (DFs) relevant to the decision process regarding SACT-PI in an interprofessional context applicable in routine clinical cancer care.

METHODS

We used a mixed methods approach, beginning with focus groups (FGs) and ending in a Delphi survey. FGs⁴⁰ were conducted with patients with advanced incurable cancer and clinicians from a tertiary cancer center (St. Gallen, Switzerland) to explore factors relevant for decisions on SACT-PI. FGs were selected in part because contributions amongst group participants may trigger the sharing of

specific individual experiences, particularly in the context of PC.⁴¹ Using the decision factors generated from the FGs, we conducted a Delphi survey to determine the level of participant agreement on the relative importance of the factors.⁴² Previous studies have applied this combination of methods.^{43,44} The local ethics committee approved the study.

FG participants and sampling

Patients were approached for FG participation if they had a predefined disease situation in which further treatment was subject to considerable balancing by the oncologist (defined by the disease specialists of the cancer center for the specific cancer entities; [Supplementary Table S1](https://doi.org/10.1016/j.esmoop.2022.100496), available at <https://doi.org/10.1016/j.esmoop.2022.100496>). They also had to have been involved in a decision-making process for or against palliative chemotherapy and confirmed cognitive ability to participate in the FG by their treating oncologist. Patients had to speak and understand German well. We used consecutive convenience sampling of all inpatients and outpatients and considered a balanced, diverse group, representing patients with and without actual SACT and main tumor types. A medical research fellow (NKM) from the section oncological palliative medicine recruited participants in the clinic in person or by phone. Patients received reimbursement of travel costs only.

For the clinician FGs, we used convenience sampling to assemble groups of experienced medical oncologists, GPs, and nurses at inpatient or outpatient oncology and palliative clinics.

Oncologists and senior clinical fellows from a tertiary cancer center ($n = 40$) and regional practicing general oncologists ($n = 7$) were randomly selected to be informed about the study and invited to participate. The final purposive sampling for two FGs assured the participation of both cancer center oncologist and practicing oncologist, and a diverse representation of oncology subspecialists.

Nurses involved in oncology or PC ($n = 40$) and a random selection of 10 out of 54 home care nurses from various regional services were invited. The final sampling included outpatient oncology, home care, PC inpatient and palliative consult service nurses.

From a publicly available database including 1000 GPs located in northeastern Switzerland, we selected by random sampling 110 who received a personal invitation to participate in the study. GPs were included if they cared for two or more patients with advanced cancer considering SACT-PI in the past 2 years. The final sampling assured the participation of younger and older, rural and urban, single and group practice GPs, and one or more GPs with reported dispute concerning SACT-PI.

Both patients and professionals provided written informed consent. Patients completed a Mini-Cog to screen for potential cognitive impairment. All participants completed a sociodemographic questionnaire, and specific questions, from either psychometric validated questionnaires or study-specific single questions (overview of

assessments and original wording in German in supplement). Physicians and patients (not nurses) reported on their decision-making preferences using the Control Preference Scale,⁴⁵ which is a single choice among five specific statements for patient-directed, shared, or oncologist-directed decision-making. Patients completed also the Edmonton Symptom Assessment Scale⁴⁶ to assess their symptom burden, and they answered questions based on Ahn et al⁴⁷ concerning their perceptions of their illness. Disease-related information was collected from medical records. Physicians and nurses were asked additional questions on their attitudes and practices regarding decision making [involvement of family in decision by oncologist, decision as event or process and perceived paternalism (oncologist only); involvement of nurse in decision-making (nurse only)], spiritual care, and their personal religion/spirituality.⁴⁸ Physicians also reported their routinely applied PC interventions using five questions based on Jacobsen et al.¹² Details on topics, measures, and response format for all questions are provided in the supplement (Supplementary Table S2, available at <https://doi.org/10.1016/j.esmoop.2022.100496>).

Running the FGs and analysis

A double-boarded oncologist/PC specialist (FS) and a psychologist (KR) conducted separate FGs for patients, physicians, and nurses. If patients preferred, they could choose an individual interview. The interview guideline (supplement) included an open, exploratory question on the topic and a range of factors considered relevant for decision-making in this phase of life. Questions were developed based on our own unpublished systematic literature review,⁴⁹ and the professional experience of the interviewers. New themes generated in prior FGs were included in subsequent FGs.

FG discussions were audio-recorded and transcribed verbatim before thematic content analysis⁵⁰ using atlas.ti.07. To establish the coding structure, two researchers (KR, NKM) independently coded a selection of transcripts. A deductive approach was used based on items from the interview guideline to identify topics and themes relevant to decision-making. In parallel, an inductive, data-driven approach was employed to identify additional topics and themes. The two coders discussed code names and definitions in-depth until consensus was reached. Subsequently all material was double-coded. The resulting list of codes was reduced by in-depth discussions among three researchers (KR, NKM, FS), applying the principles of paraphrasing, grouping, and integration⁵⁰ and by verifying the new categories based on the original quotations.

Delphi survey and analysis

For the Delphi survey, codes were rephrased as statements, each addressing a factor considered to be important in decisions for/against SACT-PI. A professional translator was responsible for the English version of all statements. By the time the Delphi survey commenced, almost all patient participants had died. Because the intention of this step was to

estimate the level of agreement on the importance of factors to be considered in SACT-PI decisions, rather than finding consensus, no new patients were recruited. Thus, the Delphi process only included clinicians who had participated in the FGs. In addition, five international experts in palliative cancer care were invited to respond to the Delphi survey. Participants completed the two-round Delphi survey online hosted on SurveyMonkey. In the first round, participants were asked to anonymously rate the importance of each statement for SACT-PI decision-making (scale: 0 = I do not agree; 10 = I fully agree). They could also comment on statements and suggest changes. The second round presented revised statements along with comments and minimal, median, and maximal ratings by physicians and nurses, respectively, so that respondents could re-rate each statement considering the group rating.^{51,52} The definition of a statement reaching 'agreement'⁵³ was based on a statement meeting all three of the following criteria: (i) agreement mean value >7; (ii) a score ≥ 7 by 80% of respondents; and (iii) a score ≥ 7 rated by the international experts.

Integrating DFs in the decision-making process

The results of the Delphi survey made clear that it was necessary to incorporate the identified DFs relevant in the processes of clinical decision-making, although we did not anticipate this research question. Based on existing literature,^{35,54-56} one author (NKM) proposed a conceptual model with five main elements of the decision-making process: (i) patient and family (predisposition, independent of current clinician); (ii) clinician and system (predisposition, independent of patient); (iii) clinician—patient interaction (individual patient with his/her individual clinician); (iv) information and patient education (including communicative and coordinative interventions delivered by the team); and (v) risk—benefit weighing and actual decision.^{35,36,54,55} Three authors (NKM, KR, FS) independently assigned DFs to one of these five elements of the decision-making process. The three authors compared their assignments, discussed disagreements, and then re-assigned until they reached consensus.

SACT-PI decision framework

To integrate the retrieved DFs in the decision-making process of SACT-PI, we reviewed literature for systematic or systematized reviews on decision-making and implementation in oncology and for key concepts of integrated oncology and PC. The scoping literature review retrieved 102 quotations on decision making and 62 on implementation, and after further hand search and snowballing, 31 papers were consulted (citations: see [Supplementary Material](#), available at <https://doi.org/10.1016/j.esmoop.2022.100496>). Models^{35,57-59} and concepts characterizing collaborative multi-professional environments and communicative and self-reflective competences of involved professionals, a key PC domain, were mainly considered. The SACT-PI Decision Framework was generated using an iterative visualization process, continuously comparing

whether results matched the model, until consensus was reached.

RESULTS

Participant characteristics

Eight FGs and one private patient interview were conducted (Figure 1). Patients had various incurable cancer diseases diagnosed since 2 years (median), their perceived symptom burden was adequately controlled, and they had an ample

illness and treatment understanding (Table 1). Sixty-seven percent (10/15) had active chemotherapy (trabectedin, carboplatin/paclitaxel, vinorelbine, oxaliplatin/gemcitabine, gemcitabine ($n = 3$), cabazitaxel, FOLFIRI, FOLFOX). Physicians were predominantly experienced oncology specialists and GPs who reported routinely applying PC interventions (Table 1). Nurses had professional experience of at least 2 years, worked in oncology and PC settings, and most reported a combination of the two in their current practice (Table 1).

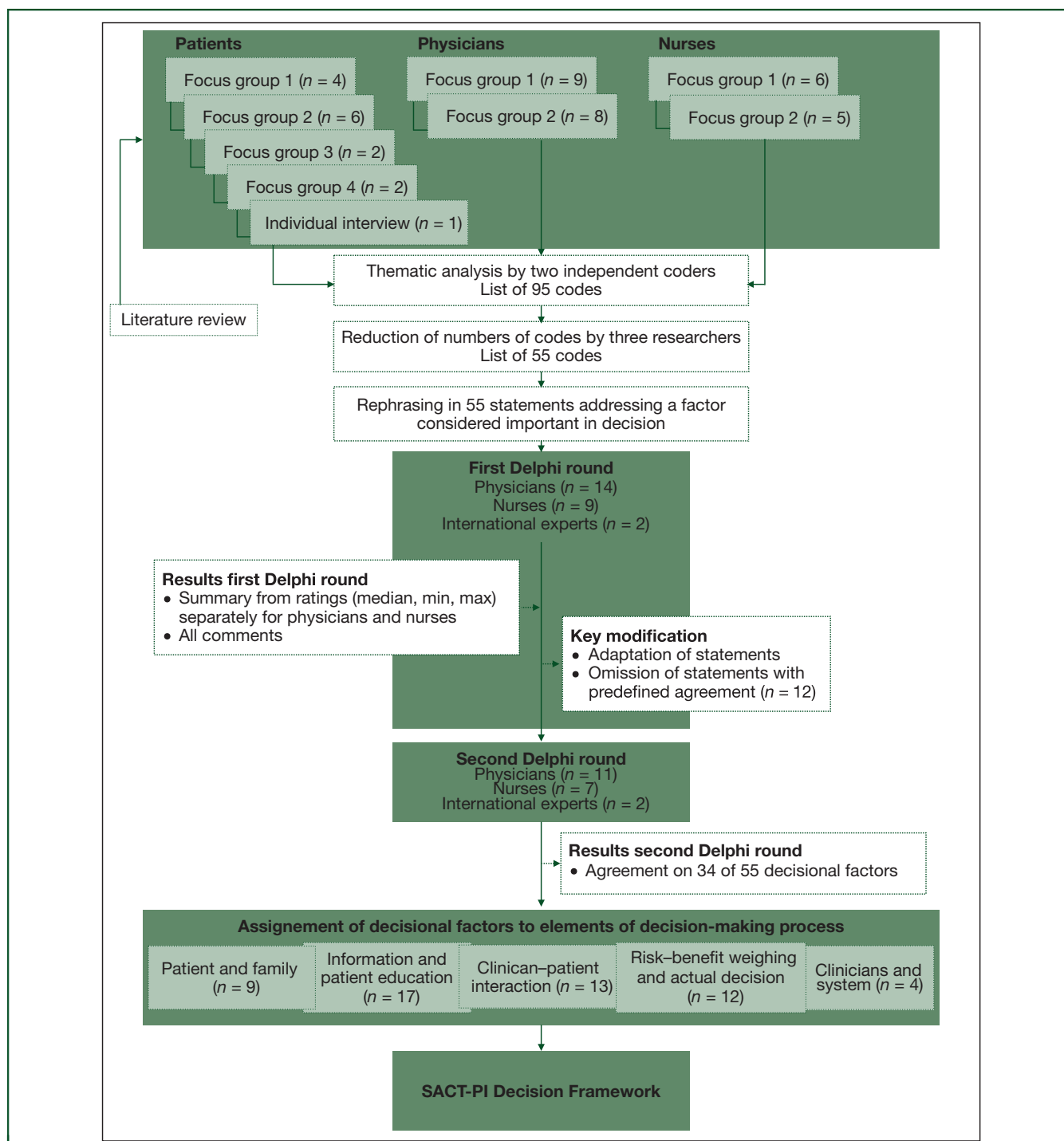


Figure 1. Flow of study procedure.

Table 1. Characteristics of participants (patients and clinicians)	
Patients (n = 15)	
Age, median (min, max)	
Years	66 (22, 82)
Sex, n (%)	
Male/female	8/7 (53)
Education, n (%)	
Basic/advanced	7/8 (47)
Living situation, n (%)	
With partner or other persons/alone	14/1 (93)
Marital status, n (%)	
Married/common law	12 (80)
Divorced/separated	2 (13)
Never married	1 (7)
Tumor type, n (%)	
Gastrointestinal	7 (47)
Lung	3 (20)
Gynecologic and breast	2 (13)
Urological	1 (7)
Other	2 (13)
Current line of systemic anticancer therapy, n (%)	
No systemic anticancer therapy	5 (33)
First line	2 (13)
Two or more lines	8 (53)
Goal of systemic anticancer therapy (multiple answers possible), n (%)	
Symptom prevention	8 (53)
Symptom treatment	7 (47)
Life prolongation	6 (40)
Karnofski performance index, n (%)	
>60 (able to care for most personal needs)	8 (53)
≤60 (unable to care for most personal needs)	6 (40)
Not specified	1 (7)
Course of events, median (min, max)	
Time since cancer diagnosis (months)	24.6 (3, 56)
Time last chemotherapy to death (weeks, n = 11)	11 (3, 25)
Survival from focus group conduction (weeks)	14.3 (2, 40)
Patients' perception of illness and treatment ^a , median (min, max)	
Awareness of diagnosis	4 (3, 4)
Awareness of prognosis	3 (2, 4)
Understanding of treatment options	3 (1, 4)
Goal of treatment is symptom control	4 (1, 4)
Goal of treatment is cure of disease	4 (1, 4)
Symptom control more important than cure	3 (1, 4)
Understanding of potential toxicities	4 (1, 4)
Health professional support for coping with disease	4 (3, 4)
Family support for coping with disease	4 (4, 4)
Thinking about end-of-life preparation	4 (2, 4)
Fight disease and thinking about end-of-life preparation	4 (2, 4)
End-of-life preparation important	4 (2, 4)
Decision-making preferences ^b , n (%)	
Doctor-directed decision	8 (53)
Shared decision	5 (33)
Patient-directed decision	1 (7)
Not specified	1 (7)
Symptom burden ^c , median (min, max)	
Tiredness	5 (1, 9)
General well-being	4 (1, 9)
Lack of energy	4 (1, 8)
Lack of appetite	3 (1, 10)
Breathlessness	2 (1, 7)
Pain	2 (1, 5)
Depression	2 (1, 4)
Anxiety	2 (1, 4)
Constipation	1 (1, 8)
Vomiting	1 (1, 8)
Nausea	1 (1, 4)

Continued

Table 1. Continued		
Clinicians	Physicians (n = 17)	Nurses (n = 11)
Age, years, n (%)		
20-29	—	3 (27)
30-39	4 (24)	1 (9)
40-49	8 (46)	5 (46)
50-59	4 (24)	2 (18)
60+	1 (6)	—
Sex, n (%)		
Female	6 (35)	10 (91)
Male	11 (65)	1 (9)
Specialization and experience of physicians, n (%)		
Oncologist	12 (70)	n.a.
General oncologist	3	n.a.
Subspecialized oncologist		
Gastrointestinal oncology	2	n.a.
Thoracic oncology	1	n.a.
Gynecological and breast oncology	2	n.a.
Hemato-oncology	2	n.a.
Other	2	n.a.
General practitioner (GPs)	5 (30)	n.a.
Years in oncology/general practice; median (range)	10 (2-17)	n.a.
Field of work and experience of nurses, n (%)		
Field of work		
Mainly oncology	n.a.	2 (18)
Mainly palliative care	n.a.	2 (18)
Mixed	n.a.	7 (41)
Type of work		
Mainly inpatients	n.a.	8 (73)
Mainly outpatients	n.a.	3 (27)
Years of work of experience, n (%)		
2-5	n.a.	4 (36)
6-10	n.a.	2 (18)
+10	n.a.	5 (46)
Training, n		
Physician communication training	12/17	n.a.
Palliative care training	11/17	7/10 ^j
Clinical experience in oncology	3/5 (GPs)	5/10 ^j
Proportion of patients with advanced cancer, n (%)		
>70%	6 (35)	7 (64)
30%-70%	5 (29)	2 (18)
<30%	1 (6)	2 (18)
Not specified	5 (29)	—
Decision-making preferences ^b , n (%)		
Patient-directed decision	8 (47)	n.a.
Doctor-directed decision	6 (35)	n.a.
Shared decision	2 (12)	n.a.
Not specified	1 (6)	
Attitudes regarding decision making, median (min, max)		
Family involvement by physician in decision ^d	3 (2, 4)	n.a.
Self-perceived involvement in decision by		
Patient/proxies	n.a.	3 (2, 4)
Physicians	n.a.	2 (1, 3)
Perceived paternalism ^f	2 (2, 3)	n.a.
Decision as a process/single event (y/n)	17/0	n.a.

Continued

Table 1. Continued

Clinicians	Physicians (n = 17)	Nurses (n = 11)
Attitudes regarding spiritual care, personal religiosity/spirituality, median (min, max)		
Frequency patients with advanced cancer should receive spiritual care ^g	4 (1, 7)	6 (3, 7)
Personal religiosity ^h	2 (1, 4)	2 (1, 4)
Personal spirituality ^h	2 (1, 4)	3 (1, 4)
Applied palliative care interventions ⁱ , median (min, max)		
Symptom screen and management	4 (3, 4)	n.a.
Addressing illness understanding and prognosis	4 (3, 4)	n.a.
Discussing goals of anticancer therapy	4 (2, 4)	n.a.
Coordination of palliative support networks	3 (2, 4)	n.a.
Preparation for end of life	3 (1, 4)	n.a.

GPs, general practitioners.

^aPerceptions of illness and treatment (adapted from ⁴⁷).

^bControl Preference Scale (⁴⁵).

^cEdmonton Symptom Assessment Scale (scale range 1-10; higher scores indicate worse condition) (⁴⁶).

^dFamily involvement by physician in decision: 1 = never, 2 = almost never, 3 = rarely, 4 = sometimes, 5 = often, 6 = almost always, 7 = always.

^eInvolvement of nurse in decision: 1 = not at all, 2 = a little bit, 3 = quite, 4 = very much.

^fPaternalism defined as acting against inauthentic (patient's) preferences 1 = never, 2 = rarely, 3 = often; 4 = very often (adapted from ⁶⁰).

^gSpiritual care: 1 = never, 2 = almost never, 3 = rarely, 4 = sometimes, 5 = often, 6 = almost always, 7 = always (adapted from ⁴⁸).

^hReligiosity and spirituality: 1 = not at all, 2 = a little bit, 3 = quite, 4 = very much (adapted from ⁴⁸).

ⁱApplied palliative care interventions: 1 = never, 2 = rarely, 3 = often; 4 = very often; (adapted from ¹²).

^jOne nurse did not answer this question.

DFs generated from FGs

The two independent coders identified 95 codes with a level of agreement on ~ 75% of codes. For the identification of codes we did not use the results of the scoping literature review. These initial codes were eventually reduced to 55 codes and rephrased as statements representing DFs (Table 2 and Supplementary Table S3, available at <https://doi.org/10.1016/j.esmoop.2022.100496>). A substantial number of DFs related to psychosocial issues experienced by patients and their families encompassing patients' hopes, attitudes, and beliefs, patients' instrumental and emotional support, and family burden. Other factors addressed procedures of the health care system and specific attitudes of the clinicians. Many DFs related to the patient's view of the clinician's skills as a communicator, trust in the clinician, and characteristics specific to individual clinicians. Further DFs addressed information giving and verification of the patients' understanding regarding treatment effects and the trajectory of illness. PC topics included end-of-life preparation and the opportunity to discuss sensitive topics. Finally, 'classic' DFs emerged such as weighing risks and benefits, defining goals, and the persons involved in the decision.

Clinicians' agreement on importance of DFs

Of the 28 clinicians from the FGs and the five international experts (total N = 33), 25 (76%) participated (14 physicians, 9 nurses, 2 experts) in the first round of the Delphi survey

(Figure 1). In the second round, 20/25 (11 physicians, 7 nurses, 2 experts) participated. Agreement was reached for 34/55 (62%) DFs on their importance for decisions guiding SACT-PI (Table 2). Agreement was reached for most of the DFs relating to the clinician–patient relationship, patient education, and general information giving. In contrast, importance ratings were ambiguous for DFs related to patients' hopes, attitudes, and beliefs, and to the meaning of remaining or prolonged lifetime.

Decision process elements and framework for SACT-PI

A total of 41 (78%) DFs were instantly assigned to one of the five decision process elements, whereas 14 required discussions within the research team until assignment, reflecting some overlap of the elements (Table 2). The elements are illustrated by exemplary quotations (Table 3).

As the first step towards the SACT-PI Decisional Framework, the decision process elements and individual factors were visualized by considering key elements of cancer PC and decisional models (references see Supplementary Material, available at <https://doi.org/10.1016/j.esmoop.2022.100496>). Assessment and communicative interventions are sentinel elements of integrated oncology and PC,²⁴ therefore we linked: patients/family by 'assessment' to clinicians/system and coordinative/logistics interventions by 'information and patient education' to communicative interventions (Supplementary Figure S1, available at <https://doi.org/10.1016/j.esmoop.2022.100496>). Second, considering the importance of patient empowerment by education and information in PC, we combined them as steps (Supplementary Figure S2, available at <https://doi.org/10.1016/j.esmoop.2022.100496>).^{12,16,61} Likewise, appreciating the multi-professional team striving to esteem patient and families' values by also reflecting own roles and biases, the steps verify and reflect were included.^{18,28,62} To appreciate the interrelation of discussion and weighing as a dynamic process, including also pauses, three steps were included.^{35,55} Third, the steps were aligned in a linear process including a balance (Supplementary Figure S3, available at <https://doi.org/10.1016/j.esmoop.2022.100496>). For the final SACT-PC Decisional Framework (Figure 2) the headings were specified. The interrelated themes 'Assess patient and family' and 'Educate and inform patient' were visually coupled as the following themes, 'verify information and reinforce relationship' and 'reflect own role as clinician'. Our results underpin the importance of the four steps assess and educate, and verify and reflect. On this basis, the next four steps of the decisional process, which is often circular not linear,^{34,36} are discuss, weigh, pause, and either decide or discuss again.

DISCUSSION

Traditionally, decisions regarding SACT-PI involve information provision and risk–benefit analysis^{29,63} including the patient's preferred involvement in decision-making.⁶⁴ Our study identified additional DFs, which seem relevant for such challenging decisions, including various subjective patient

Table 2. Individual 55 factors with agreement on importance for a decision by Delphi survey

	Agreement on importance of factor based on Delphi survey	Agreement on assignment of factor to element of decision-making process	Decision on assignment to a decision process element by consensus	Arguments for decision on assignment
Clinician in agreement with patient decides in complex situation	a	2/3	Risk—benefit weighing	Actual decision important
Patient decides himself/herself	y	2/3	Risk—benefit weighing	Trustful relationship important
Offer to involve family members in decision	y	2/3	Information and patient education	Coordinative education, offer the team not oncologist
Offer to involve further specialists in decision	y	2/3	Information and patient education	Coordinative education, offer the team not oncologist
Ensuring good communication	y	3/3	Clinician—patient interaction	
Existence of basis of trust	y	3/3	Clinician—patient interaction	
Humanity/sympathy/honest interest of clinician	y	2/3	Clinician—patient interaction	Patient-perceived, not lone standing oncologist
Patient-perceived clinician's competence	y	2/3	Clinician—patient interaction	Patient-perception of individual clinician
Patient-perceived clinician's honesty	y	2/3	Clinician—patient interaction	Patient-perception of individual clinician
Patient-perceived clinician's communicative abilities	y	2/3	Clinician—patient interaction	Patient-perception of individual clinician
Clinician's knowledge of patient's situation	y	3/3	Clinician—patient interaction	
Patient's feeling not being a stranger to clinician	a	2/3	Clinician—patient interaction	Dependent on individual patient and clinician
Willingness of patient and clinician to trust and go on the journey together	a	3/3	Clinician—patient interaction	
Clinician's intuition during decisional process	y	3/3	Clinicians and system	
Inner conviction of clinician leads to unbalanced discussions	a	3/3	Clinicians and system	
Being in good hands with health care team	y	2/3	Clinician—patient interaction	Not patient precondition unable to trust, but reality
Stability of patient's relationship to clinician	y	3/3	Clinician—patient interaction	
Offer to discuss existential topics with treatment team	y	3/3	Information and patient education	
Practical burden on patient's family	y	3/3	Risk—benefit weighing	
Emotional burden on patient's family	y	3/3	Patient and family	
Support of patient by family	y	3/3	Patient and family	
End-of-life preparations although CHT	y	3/3	Information and patient education	
Understanding when inhibition of tumor growth	a	3/3	Information and patient education	
Understanding of medical values	a	3/3	Information and patient education	
Monitoring of patient understanding of information	y	3/3	Information and patient education	
Monitoring of patient understanding of illness	y	3/3	Information and patient education	
Patient overwhelmed by coping with illness	y	3/3	Patient and family	
Exploring possible fears	y	3/3	Information and patient education	
Planning time for consideration	y	2/3	Information and patient education	Information to patient of current standards, before the decision, not interactional
Neglecting end-of-life issues due to CHT activities	a	3/3	Clinicians and system	
Meaning of hope for patient	y	3/3	Patient and family	
Doing everything even though benefit unlikely	a	3/3	Patient and family	
Hope connected with CHT	a	3/3	Patient and family	
CHT same effect as preceding CHTs	a	3/3	Patient and family	
CHT better effect if believed in it	a	3/3	Patient and family	
CHT better effect if mental/emotional state good	a	3/3	Patient and family	
General willingness to undergo CHT	a	3/3	Patient and family	
Informational discussions prepared/planned	y	2/3	Information and patient education	Clinical standards of coordination
Amount of information during trajectory of illness	a	3/3	Information and patient education	
Information on CHT administration/side-effects	y	3/3		

Continued

Table 2. Continued

	Agreement on importance of factor based on Delphi survey	Agreement on assignment of factor to element of decision-making process	Decision on assignment to a decision process element by consensus	Arguments for decision on assignment
Information about treatment options	y	3/3	Information and patient education	
Customized planning and logistics of CHT	a	3/3	Information and patient education	
Regular evaluation of CHT effects and possibility of discontinuation	y	3/3	Information and patient education	
Goals defined	y	2/3	Information and patient education	Goals are important before balancing
Weighing individual benefit versus cost	y	3/3	Risk–benefit weighing	
Financial costs of CHT	a	3/3	Risk–benefit weighing	Financial toxicity
Meaning of prolonged survival time	a	2/3	Risk–benefit weighing	Balancing in the current situation expected OS benefit, with concrete goals
Use of remaining lifetime	a	3/3	Risk–benefit weighing	Concrete use in daily life
Impact of side-effects on QoL	y	3/3	Risk–benefit weighing	
Impact of cancer on QoL	y	2/3	Risk–benefit weighing	Direct dependence on actual chemotherapy
CHT improves QoL	y	3/3	Risk–benefit weighing	
CHT improves physical function	a	3/3	Risk–benefit weighing	
CHT alleviates symptoms	y	3/3	Risk–benefit weighing	
Health care team change without CHT	a	3/3	Clinicians and system	
CHT for family	a	3/3	Patient and family	

Shaded columns show assignment to elements of decision-making process.

a, ambiguous; CHT, chemotherapy; OS, overall survival; QoL, quality of life; y, yes.

factors, interpersonal factors, and PC issues. A key finding is the understanding that decisions regarding SACT-PI pertain to a process, not a single act, and that this process involves a sequence of interrelated coupled themes: first assess and educate, then verify and reflect, followed by the circular discuss-weigh-pause-decide process. These concrete steps are designed to guide the use of SACT-PI in an interprofessional clinical context and shall be considered as integral components of the decision-making process in the future.

DFs assigned to the process elements ‘information and patient education’ as well as ‘weighing risk–benefit and actual decision’ are covered in available, disease-specific DAs for advanced cancer patients.^{29,63} The explicit clarification of decision-making preference,⁶⁵ usually an integral part of DAs, was not identified as a DF in our study. We hypothesize that the patient’s view of and involvement in decision-making may be a product of taking subjective and relational factors and PC domains into account, which were explicitly characterized in our study. Clarification of the individual meaning of cost and benefit of anticancer treatment played a prominent role in our results. These factors are less addressed in traditional DAs. Our findings also highlight that for SACT-PI, decision-making is not restricted to the patient and physician but the collaboration of various additional actors (family, multidisciplinary team).³⁵

DFs related to PC and end-of-life issues are covered partially in existing question prompt lists for patients with advanced cancer.^{66,67} These lists, however, are not

customized to explicitly address PC domains in the context of a decision for or against chemotherapy, and patients tend to ask questions mainly from the prognosis section.^{68,69} Our data suggest that PC and end-of-life factors should play a more prominent role in the SACT-PI decision-making process.

We also identified subjective DFs³² that have been less addressed so far, such as those related to hope, attitudes, and beliefs.^{70,71} Conventional DAs aim to capture this subjective evidence by relatively simple ‘weigh scales’ to assist patients in becoming clearer about how much and why they value an option (so called ‘value clarification exercises’).³² Subjective evidence depends on mental representations of information, which may not be the verbatim information but rather the subjective interpretation of it.⁷² Such perceptions of reality shape decision-making, sometimes ‘outside of conscious awareness’.⁷³ This mechanism may explain why those factors, resulting from a balancing process in the patient’s personal context,⁷⁴ are scarcely applied in the typical medical context. Our DFs related to hope cover both a particular hope that aims at precise goals as well as a generalized hope implying absolute trust in the future without any specific predetermined goals.⁷⁵ The clinicians in our sample were ambiguous regarding the importance of factors related to hope, attitudes, and beliefs for decision-making. This may reflect a general underestimation of subjective evidence, as previously reported.^{70,74}

Quite a number of DFs cover the clinician–patient interaction and correspond with the conceptualization of trust in

Table 3. Elements of decision-making process: examples of quotations

Patient and family
Patients are overwhelmed by the situation; they must adapt first. This must not be underestimated. (Patient, C51)
In the end, it's your belief that determines whether the chemotherapy is effective or not. This is essential for me. If I want an improvement, I have to believe that it works. (Patient, C26)
If I undergo chemotherapy, I believe in hope. (Patient, C7)
If a patient experiences a lot of anxiety, particularly young persons, they do not want to die, and they grasp at straws, then I can understand the physician who doesn't like to say it's better to not give chemotherapy than to give palliative chemotherapy, but instead says we can try further chemotherapy. But sometimes I find it difficult when we know that it will not help any more, but we offered it to comfort the patient. (Nurse, C6)
It should be considered from the beginning how we can support the patient's family or address what the family members need, because sometimes we forget about them, and we require a lot from them. (Nurse, C29)
Clinicians and system
I try within the time I have available, sometimes I need 2-3 contacts, and sometimes it is enough to share the time walking along the hallway to sense certain things. (Physician, C45)
A doctor that knows me will see that something is wrong with me, that my face is yellow. But if I go to a new doctor, he will not notice. (Patient, C42)
The core business [of palliative care] is neglected due to chemotherapy and suddenly there are just three days left, and almost no time due to the patient's health status to address existential issues or issues important to the patient. (Nurse, C52)
Clinician-patient-interaction
I had several oncologists, and I was surprised that each of them knew who I was, what I do, and what I prefer. I asked myself whether they had exchanged this information or how do they know it? I found it very agreeable, and I had full trust in each of them. (Patient C42)
Information and patient education
There are patients who want to know every detail—and they can cope with this information, while others cannot cope with too much detailed information; they are overwhelmed. (Nurse, C15)
It is important to tell the patient that he/she can always stop chemotherapy [...] or that we can try and see how he/she tolerates it, but that he/she can stop it anytime. (Physician, C21)
The doctor could have told me more, how I will feel, how bad I will feel, and what I will have to struggle with. (Patient, C18)
Risk-benefit-weighting and actual decision
What is the current benefit for the patient, what is the range of side-effects he can expect, and how many good months are there in the end? Not only the months under treatment but the good months as well. If a patient has all the facts on the table, he/she can decide whether he/she will get on board and whether it is worth it. (Physician, C54)
For me it is clear that [...] without chemotherapy I have a better quality of life, even if it shortens my life. Therefore, I will live until then, try to be in a good mood and enjoy those things I still can do. (Patient, C5)
The patient's quality of life must be addressed, and what constitutes quality of life must be defined. What does quality of life mean to the patient? [...] It is not a black box, but everybody has a different idea of what it means. The crucial criterion is what quality of life means to the individual patient. (Physician, C10)

clinicians in general⁷⁶ and oncologists specifically⁷⁷ as overlapping dimensions of global trust, fidelity, competence, and honesty. Cancer patients have a strong need to trust in their oncologist and a deeper, more emotional bond of trust can be developed only after repeated interaction,⁷⁸ two aspects that were clearly expressed by the patients during the FG discussions. Our results are consistent with the observation that in the advanced cancer setting, DAs and prompt lists may not facilitate decision-making without the sensitive endorsement by a clinician.⁶⁸ Strikingly, some of our DFs related clearly to clinicians' self-reflection and the role of intuition. This finding may be similar to the core attitudes described for professionals in PC, including honesty, perception, involvement, and intuition,^{71,79} and is supported by a recent review that identified the predisposition of involved people and interactional aspects to be facilitators or barriers to shared decision-making.³⁶ The SACT-PI Decision Framework seems applicable to modern oncology because the decision process is not based on prognostication, but on values, processes, and human interactions and may harmonize the often overrated hope linked to new anticancer treatments.⁸⁰

Limitations

This study was conducted at a European Society for Medical Oncology designated center of Integrated Oncology and PC.⁸¹ The SACT-PI Decision Framework may be different in other multidisciplinary cancer care settings.²⁵ Our patients were all from the eastern, German-speaking part of

Switzerland, a population with 25% foreigners, 50% having tertiary education and a low likelihood of poverty. Their view on DFs may not be representative for patients with a diverse cultural background and socioeconomic status. Decisional processes may be influenced by local cultures. For instance, certain topics such as spiritual care¹³ and faith⁷⁰ did not emerge during our FG discussions despite prompts from the moderators. The preference for a 'passive' or 'doctor-directed' decision was high (53%, 8/15) compared with a median of 27% reported in studies conducted worldwide.⁸² The passive role was more frequent in Western (36%) compared with Asian (28%) countries, and in advanced (46%) versus early-stage (31%) cancer. The preference for a passive role in our patient population is consistent with systematic reviews in lung and colorectal cancer patients.^{83,84}

In the context of the present Swiss health care system, nurses rarely have an explicit, independent role in their care for patients, which is quite different from other countries where both nursing and physician consultations on medical end-of-life decisions are common.^{61,85,86} In Switzerland, care provided by specialized, advanced practice nurses is only recently gaining traction.⁸⁷ Therefore, the application of our SACT-PI Decision Framework to local clinics requires adaption to the roles and norms of the health care context.

Our findings may be enriched by more FGs with clinicians, even though we approached saturation,⁸⁸ and by bigger patient FGs.⁴¹ In small groups participants are more likely to be involved emotionally.⁸⁸ Also, the Delphi process, used as internal validation,⁸⁹ may be expanded to patients.

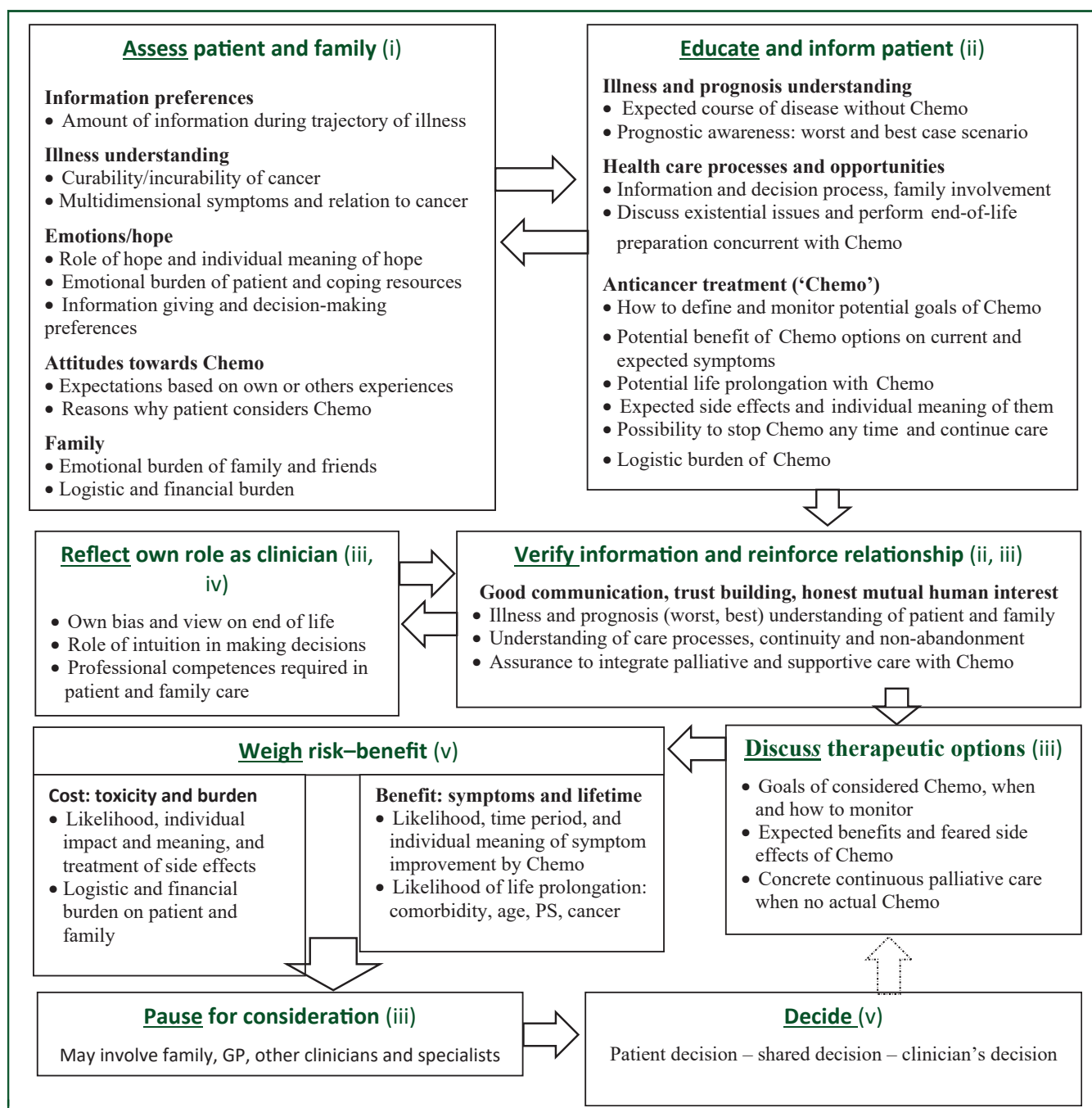


Figure 2. Systemic anticancer treatment with palliative intent (SACT-PI) decision framework.

Elements of decisional factors: subjects: (i) patient and family, (ii) clinician and system, (iii) interaction of clinicians and patients; actions: (iv) information and patient education, (v) risk-benefit weighting and actual decision.

Chemo, chemotherapy; GP, general practitioner, PS, performance status.

Clinical implications and future research

This study deepens our understanding of factors relevant for decision-making in advanced, incurable cancer, a clinical setting where patient expectations about the effects of SACT-PI may be inaccurate, compromise decision-making, and lead to high cancer costs for a small benefit.⁹⁰ Currently, the inclusion of patient/family and emotional issues is promoted as well as participative and supportive behavior in addition to traditional medical and technical issues.⁶² Likewise, early integration of palliative

interventions is becoming standard of care,^{19,25} and the role of specialized advanced practice nursing is emerging.³⁹ The inclusion of a time out—to involve GPs—or a pause is a timely demand.^{91,92} The novel SACT-PI framework complements existing DAs and prompt lists by including themes related to the clinician–patient relationship, clinical benefit, or integrated oncology and PC and reinforcing the importance of the decision process, not the decision act.

Changing the practice of oncology clinicians can insufficiently be achieved by providing algorithms or guidelines, as shown by examples from chemotherapy-induced peripheral

neuropathy⁹³ or chemotherapy-induced nausea and vomiting.⁹⁴ In contrast, training of specific skills can be effective in improving shared decision-making.⁹⁵ Another approach is to share responsibilities and interventions in the multidisciplinary and interprofessional care team. The success of specialist PC^{17,19,21,22} or oncology nurses fostering resilience⁹⁶ are examples.

The first two coupled SACT-PI steps ‘Assess patient and family’ and ‘Educate and inform patient’ can be implemented independent of the cultural or ethnical context⁹⁷; the steps include assessing patient preference for information and involvement in decision making. Clinicians other than physicians—namely oncology nurses⁹⁶—can carry out these two steps, or physicians working in a culture and clinical pathways of integrated oncology and cancer PC can be involved.⁹⁸

The second coupled SACT-PI steps require the oncologist who ‘verifies information and reinforces relationship’ and ‘reflects own role as clinician’. A conscious, consensually agreed and lived culture of interprofessional collaboration including transprofessional education that is institutionally supported and financed,⁹⁹ may substantially improve the quality of decision processes. This includes strengthening the role of oncology nurses in decision-making processes.

For the implementation of the final four—circular—steps (discuss, weigh, pause, and decide) current DAs cover main elements. An additional important requirement would be to actively offer a pause as institutional standard of care,^{91,92} and demand a training in shared decision-making skills.⁹⁵

Further research may investigate how to best operationalize such components into an applicable and useful clinical encounter, especially when decisions are difficult.

Conclusion

Decision making for anticancer regimens should include traditional risk–benefit considerations and standard information as delineated in available DAs. We also identified patient- and clinician-related factors, interpersonal relationships, and additional PC topics to be relevant for this treatment phase. These factors represent important complements to the standard practice of decision-making and require a step-by-step decisional process that is not sufficiently addressed in traditional DAs. Our proposal of a SACT-PI Decision Framework should be further investigated in order to determine how it can be implemented into the clinical treatment pathway and if it will improve patient, clinician, and system outcomes.

ACKNOWLEDGEMENTS

For the support of this study, we thank the patients, physicians (Christian Häuptle, Dagmar Hess, Felicitas Hitz, Daniel Horber, Andreas Hochstrasser, Markus Jörgen, Nanda Meister, Iris Müller-Käser, Christian Rothermundt, Thomas Ruhstaller, Marc Schlaeppli, Tobias Silzle, Patrik Weder, Britta Hafner, Susann Heidelk, Christoph Rohrer, Patrick Scheiwiler), nurses (Gabriela Döpfner, Sandra Zähler, Beatrice Sprenger, Christina Schmitz, Sabrina Irin, Ivo Dürr,

Sibylle Romer, Steffi Pilat, Sonja Kassem, Claudia Venzin, Daniela Merk), and international experts (S Yousuf Zafar MD, Amy Abernethy, MD, Duke University Medical Center, USA). For their administrative support, we thank Daniela Zünd, Simone Wilm, and Nadine Behnke.

FUNDING

This work was supported by the Swiss Cancer League [grant number KLS-2785-02-2011].

DISCLOSURE

The authors have declared no conflicts of interest.

REFERENCES

1. Cherny NI, Sullivan R, Dafni U, et al. A standardised, generic, validated approach to stratify the magnitude of clinical benefit that can be anticipated from anti-cancer therapies: the European Society for Medical Oncology Magnitude of Clinical Benefit Scale (ESMO-MCBS). *Ann Oncol*. 2015;26:1547-1573.
2. Prigerson HG, Bao Y, Shah MA, et al. Chemotherapy use, performance status, and quality of life at the end of life. *JAMA Oncol*. 2015;1:778-784.
3. Kristensen A, Vagnildhaug OM, Gronberg BH, Kaasa S, Laird B, Solheim TS. Does chemotherapy improve health-related quality of life in advanced pancreatic cancer? A systematic review. *Crit Rev Oncol Hematol*. 2016;99:286-298.
4. Wadhwa D, Hausner D, Popovic G, et al. Systemic anti-cancer therapy use in palliative care outpatients with advanced cancer. *J Palliat Care*. 2021;36:78-86.
5. LeBlanc TW, Temel JS, Helft PR. “How Much Time Do I Have?”: communicating prognosis in the era of exceptional responders. *Am Soc Clin Oncol Educ Book*. 2018;38:787-794.
6. Simmons C, McMillan DC, Tuck S, et al. “How long have I got?” — a prospective cohort study comparing validated prognostic factors for use in patients with advanced cancer. *Oncologist*. 2019;24:e960-e967.
7. Chu C, Anderson R, White N, et al. Prognosticating for adult patients with advanced incurable cancer: a needed oncologist skill. *Curr Treat Options Oncol*. 2020;21:5.
8. Weeks JC, Catalano PJ, Cronin A, et al. Patients’ expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012;367:1616-1625.
9. Enzinger AC, Uno H, McCleary N, et al. Effectiveness of a multimedia educational intervention to improve understanding of the risks and benefits of palliative chemotherapy in patients with advanced cancer: a randomized clinical trial. *JAMA Oncol*. 2020;6:1265-1270.
10. Earle CC, Landrum MB, Souza JM, Neville BA, Weeks JC, Ayanian JZ. Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J Clin Oncol*. 2008;26:3860-3866.
11. Peppercorn JM, Smith TJ, Helft PR, et al. American society of clinical oncology statement: toward individualized care for patients with advanced cancer. *J Clin Oncol*. 2011;29:755-760.
12. Jacobsen J, Jackson V, Dahlin C, et al. Components of early outpatient palliative care consultation in patients with metastatic nonsmall cell lung cancer. *J Palliat Med*. 2011;14:459-464.
13. Phelps AC, Lauderdale KE, Alcorn S, et al. Addressing spirituality within the care of patients at the end of life: perspectives of patients with advanced cancer, oncologists, and oncology nurses. *J Clin Oncol*. 2012;30:2538-2544.
14. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300:1665-1673.
15. Laidsaar-Powell R, Butow P, Bu S, et al. Family involvement in cancer treatment decision-making: A qualitative study of patient, family, and clinician attitudes and experiences. *Patient Educ Couns*. 2016;99:1146-1155.
16. Schildmann J, Ritter P, Salloch S, Uhl W, Vollmann J. ‘One also needs a bit of trust in the doctor ...’: a qualitative interview study with

- pancreatic cancer patients about their perceptions and views on information and treatment decision-making. *Ann Oncol.* 2013;24:2444-2449.
17. Haun MW, Estel S, Rucker G, et al. Early palliative care for adults with advanced cancer. *Cochrane Database Syst Rev.* 2017;6:CD011129.
 18. Hui D, Hannon BL, Zimmermann C, Bruera E. Improving patient and caregiver outcomes in oncology: team-based, timely, and targeted palliative care. *CA Cancer J Clin.* 2018;68:356-376.
 19. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update. *J Clin Oncol.* 2017;35:96-112.
 20. Gaertner J, Siemens W, Meerpohl JJ, et al. Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis. *BMJ.* 2017;357:j2925.
 21. Vanbutsele G, Van Belle S, Surmont V, et al. The effect of early and systematic integration of palliative care in oncology on quality of life and health care use near the end of life: a randomised controlled trial. *Eur J Cancer.* 2020;124:186-193.
 22. Lammers A, Slatore CG, Fromme EK, Vranas KC, Sullivan DR. Association of early palliative care with chemotherapy intensity in patients with advanced stage lung cancer: a national cohort study. *J Thorac Oncol.* 2019;14:176-183.
 23. Maltoni M, Scarpi E, Dall'Agata M, et al. Systematic versus on-demand early palliative care: a randomised clinical trial assessing quality of care and treatment aggressiveness near the end of life. *Eur J Cancer.* 2016;69:110-118.
 24. Bickel KE, McNiff K, Buss MK, et al. Defining high-quality palliative care in oncology practice: an American Society of Clinical Oncology/American Academy of Hospice and Palliative Medicine Guidance Statement. *J Oncol Pract.* 2016;12:e828-e838.
 25. Dittrich C, Kosty M, Jezdic S, et al. ESMO/ASCO recommendations for a Global Curriculum (GC) in medical oncology — edition 2016. *Ann Oncol.* 2016;27:1378-1381.
 26. Strasser F, Blum D, von Moos R, et al. The effect of real-time electronic monitoring of patient-reported symptoms and clinical syndromes in outpatient workflow of medical oncologists: E-MOSAIC, a multicenter cluster-randomized phase III study (SAKK 95/06). *Ann Oncol.* 2016;27:324-332.
 27. Roncolato FT, Joly F, O'Connell R, et al. Reducing uncertainty: predictors of stopping chemotherapy early and shortened survival time in platinum resistant/refractory ovarian cancer-the GCIg symptom benefit study. *Oncologist.* 2017;22:1117-1124.
 28. Butow P, Brown R, Aldridge J, et al. Can consultation skills training change doctors' behaviour to increase involvement of patients in making decisions about standard treatment and clinical trials: a randomized controlled trial. *Health Expect.* 2015;18:2570-2583.
 29. Leighl NB, Shepherd HL, Butow PN, et al. Supporting treatment decision making in advanced cancer: a randomized trial of a decision aid for patients with advanced colorectal cancer considering chemotherapy. *J Clin Oncol.* 2011;29:2077-2084.
 30. Spronk I, Burgers JS, Schellevis FG, van Vliet LM, Korevaar JC. The availability and effectiveness of tools supporting shared decision making in metastatic breast cancer care: a review. *BMC Palliat Care.* 2018;17:74.
 31. Spronk I, Meijers MC, Heins MJ, et al. Availability and effectiveness of decision aids for supporting shared decision making in patients with advanced colorectal and lung cancer: results from a systematic review. *Eur J Cancer Care (Engl).* 2019;28:e13079.
 32. Lewllyn-Thomas HA. Values clarification. In: Edwards A, Elwyn G, editors. *Shared Decision Making in Health Care: Achieving Evidence-Based Patient Choice.* 2nd ed. New York: Oxford University Press Inc; 2009:123-132.
 33. Wright AA, Zhang B, Keating NL, Weeks JC, Prigerson HG. Associations between palliative chemotherapy and adult cancer patients' end of life care and place of death: prospective cohort study. *BMJ.* 2014;348:g1219.
 34. Herrmann A, Sanson-Fisher R, Hall A, Zdenkowski N, Waller A. A discrete choice experiment to assess cancer patients' preferences for when and how to make treatment decisions. *Support Care Cancer.* 2018;26:1215-1220.
 35. Menard C, Merckaert I, Razavi D, Libert Y. Decision-making in oncology: a selected literature review and some recommendations for the future. *Curr Opin Oncol.* 2012;24:381-390.
 36. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns.* 2014;94:291-309.
 37. Mori M, Shimizu C, Ogawa A, Okusaka T, Yoshida S, Morita T. What determines the timing of discussions on forgoing anticancer treatment? A national survey of medical oncologists. *Support Care Cancer.* 2019;27:1375-1382.
 38. Dahlhaus A, Vanneman N, Siebenhofer A, Brosche M, Guethlin C. Involvement of general practitioners in palliative cancer care: a qualitative study. *Support Care Cancer.* 2013;21:3293-3300.
 39. Albers G, Francke AL, de Veer AJ, Bilsen J, Onwuteaka-Philipsen BD. Attitudes of nursing staff towards involvement in medical end-of-life decisions: a national survey study. *Patient Educ Couns.* 2014;94:4-9.
 40. Kitzinger J. Qualitative research. introducing focus groups. *BMJ.* 1995;311:299-302.
 41. Hudson P. Focus group interviews: a guide for palliative care researchers and clinicians. *Int J Palliat Nurs.* 2003;9:202-207.
 42. Shaw JM, Price MA, Clayton JM, et al. Developing a clinical pathway for the identification and management of anxiety and depression in adult cancer patients: an online Delphi consensus process. *Support Care Cancer.* 2016;24:33-41.
 43. Fearon K, Strasser F, Anker SD, et al. Definition and classification of cancer cachexia: an international consensus. *Lancet Oncol.* 2011;12:489-495.
 44. Kaasa S, Loge JH, Fayers P, et al. Symptom assessment in palliative care: a need for international collaboration. *J Clin Oncol.* 2008;26:3867-3873.
 45. Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res.* 1997;29:21-43.
 46. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multicenter study comparing two numerical versions of the Edmonton Symptom Assessment System in palliative care patients. *J Pain Symptom Manage.* 2011;41:456-468.
 47. Ahn E, Shin DW, Choi JY, et al. The impact of awareness of terminal illness on quality of death and care decision making: a prospective nationwide survey of bereaved family members of advanced cancer patients. *Psychooncology.* 2013;22:2771-2778.
 48. Balboni MJ, Sullivan A, Amobi A, et al. Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training. *J Clin Oncol.* 2013;31:461-467.
 49. Kalbermatten Magaya N. *Non-medical factors influencing the decision making process for systemic anticancer treatment in patients with advanced cancer — a systematic literature review.* London: CSI Kings College; 2016.
 50. Mayring P. *Qualitative Inhaltsanalyse: Grundlagen und Techniken.* 11th ed. Weinheim und Basel: Beltz Verlag; 2010 (überarbeitete und aktualisierte Auflage).
 51. Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs.* 2000;32:1008-1015.
 52. Boulkedid R, Abdoul H, Loustau M, Sibony O, Alberti C. Using and reporting the Delphi method for selecting healthcare quality indicators: a systematic review. *PLoS One.* 2011;6:e20476.
 53. Biondo PD, Nekolaichuk CL, Stiles C, Fainsinger R, Hagen NA. Applying the Delphi process to palliative care tool development: lessons learned. *Support Care Cancer.* 2008;16:935-942.
 54. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med.* 1997;44:681-692.
 55. Luketina H, Fotopoulou C, Luketina RR, Pilger A, Sehouli J. Treatment decision-making processes in the systemic treatment of ovarian cancer: review of the scientific evidence. *Anticancer Res.* 2012;32:4085-4090.
 56. Joseph-Williams N, Edwards A, Elwyn G. Power imbalance prevents shared decision making. *BMJ.* 2014;348:g3178.
 57. van Vliet LM, Harding R, Bausewein C, Payne S, Higginso IJ. How should we manage information needs, family anxiety, depression, and breathlessness for those affected by advanced disease: development

- of a Clinical Decision Support Tool using a Delphi design. *BMC Med.* 2015;13:263.
58. Bélanger E, Rodríguez C, Groleau D. Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis. *Palliat Med.* 2011;25:242-261.
 59. Joseph-Williams N, Lloyd A, Edwards A, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. *BMJ.* 2017;357:j1744.
 60. Cherny NI. Controversies in oncologist-patient communication: a nuanced approach to autonomy, culture, and paternalism. *Oncology.* 2012;26:37-43, 46.
 61. Bakitas MA, Tosteson TD, Li Z, et al. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. *J Clin Oncol.* 2015;33:1438-1445.
 62. Fine E, Reid MC, Shengelia R, Adelman RD. Directly observed patient-physician discussions in palliative and end-of-life care: a systematic review of the literature. *J Palliat Med.* 2010;13:595-603.
 63. Fiset V, O'Connor AM, Evans W, Graham I, DeGrasse C, Logan J. Development and evaluation of a decision aid for patients with stage IV non-small cell lung cancer. *Health Expect.* 2000;3:125-136.
 64. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. *Soc Sci Med.* 2005;61:2252-2264.
 65. Chiew KS, Shepherd H, Vardy J, Tattersall MHN, Butow PN, Leighl NB. Development and evaluation of a decision aid for patients considering first-line chemotherapy for metastatic breast cancer. *Health Expect.* 2008;11:35-45.
 66. Walczak A, Mazer B, Butow PN, et al. A question prompt list for patients with advanced cancer in the final year of life: development and cross-cultural evaluation. *Palliat Med.* 2013;27:779-788.
 67. Yeh JC, Cheng MJ, Chung CH, Smith TJ. Using a question prompt list as a communication aid in advanced cancer care. *J Oncol Pract.* 2014;10:e137-e141.
 68. Butow P, Devine R, Boyer M, Pendlebury S, Jackson M, Tattersall MHN. Cancer consultation preparation package: changing patients but not physicians is not enough. *J Clin Oncol.* 2004;22:4401-4409.
 69. Brandes K, Butow PN, Tattersall MHN, et al. Advanced cancer patients' and caregivers' use of a Question Prompt List. *Patient Educ Couns.* 2014;97:30-37.
 70. Silvestri GA, Knittig S, Zoller JS, Nietert PJ. Importance of faith on medical decisions regarding cancer care. *J Clin Oncol.* 2003;21:1379-1382.
 71. Schildmann J, Tan J, Salloch S, Vollmann J. "Well, I think there is great variation...": a qualitative study of oncologists' experiences and views regarding medical criteria and other factors relevant to treatment decisions in advanced cancer. *Oncologist.* 2013;18:90-96.
 72. Pieterse AH, de Vries M, Kunneman M, Stiggelbout AM, Feldman-Stewart D. Theory-informed design of values clarification methods: a cognitive psychological perspective on patient health-related decision making. *Soc Sci Med.* 2013;77:156-163.
 73. Reyna VF. Theories of medical decision making and health: an evidence-based approach. *Med Decis Making.* 2008;28:829-833.
 74. Huijter M, van Leeuwen E. Personal values and cancer treatment refusal. *J Med Ethics.* 2000;26:358-362.
 75. Daneault S, Dion D, Sicotte C, et al. Hope and noncurative chemotherapies: which affects the other? *J Clin Oncol.* 2010;28:2310-2313.
 76. Hall MA, Camacho F, Dugan E, Balkrishnan R. Trust in the medical profession: conceptual and measurement issues. *Health Serv Res.* 2002;37:1419-1439.
 77. Hillen MA, Koning CC, Wilmink JW, et al. Assessing cancer patients' trust in their oncologist: development and validation of the Trust in Oncologist Scale (TIOS). *Support Care Cancer.* 2012;20:1787-1795.
 78. Hillen MA, Onderwater AT, van Zwieten MCB, de Haes HCJM, Smets EMA. Disentangling cancer patients' trust in their oncologist: a qualitative study. *Psychooncology.* 2012;21:392-399.
 79. Simon ST, Ramsenthaler C, Bausewein C, Krischke N, Geiss G. Core attitudes of professionals in palliative care: a qualitative study. *Int J Palliat Nurs.* 2009;15:405-411.
 80. Wong A, Billett A, Milne D. Balancing the hype with reality: what do patients with advanced melanoma consider when making the decision to have immunotherapy? *Oncologist.* 2019;24:e1190-e1196.
 81. Hui D, Cherny N, Latino N, Strasser F. The 'critical mass' survey of palliative care programme at ESMO designated centres of integrated oncology and palliative care. *Ann Oncol.* 2017;28:2057-2066.
 82. Noteboom EA, May AM, van der Wall E, de Wit NJ, Helsper CW. Patients' preferred and perceived level of involvement in decision making for cancer treatment: a systematic review. *Psychooncology.* 2021;30:1663-1679.
 83. Damm K, Vogel A, Prenzler A. Preferences of colorectal cancer patients for treatment and decision-making: a systematic literature review. *Eur J Cancer Care (Engl).* 2014;23:762-772.
 84. Schmidt K, Damm K, Prenzler A, Golpon H, Welte T. Preferences of lung cancer patients for treatment and decision-making: a systematic literature review. *Eur J Cancer Care (Engl).* 2016;25:580-591.
 85. Berry DL, Blumenstein BA, Halpenny B, et al. Enhancing patient-provider communication with the electronic self-report assessment for cancer: a randomized trial. *J Clin Oncol.* 2011;29:1029-1035.
 86. Walczak A, Butow PN, Clayton JM, et al. Discussing prognosis and end-of-life care in the final year of life: a randomised controlled trial of a nurse-led communication support programme for patients and caregivers. *BMJ Open.* 2014;4:e005745.
 87. Serena A, Castellani P, Fucina N, et al. The role of advanced nursing in lung cancer: a framework based development. *Eur J Oncol Nurs.* 2015;19:740-746.
 88. Morgan DL. *Focus Groups as Qualitative Research.* 2nd ed. Thousand Oaks, London, New Delhi: Sage Publications; 1997.
 89. Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *BMJ.* 2008;337:a1035.
 90. Kelly RJ, Smith TJ. Delivering maximum clinical benefit at an affordable price: engaging stakeholders in cancer care. *Lancet Oncol.* 2014;15:e112-e118.
 91. Perfors IAA, Noteboom EA, de Wit NJ, et al. Effects of a time out consultation with the general practitioner on cancer treatment decision-making: a randomised controlled trial: time out with the general practitioner and cancer treatment decision. *Psychooncology.* 2021;30:571-580.
 92. Herrmann A, Sanson-Fisher R, Hall A. Not having adequate time to make a treatment decision can impact on cancer patients' care experience: Results of a cross-sectional study. *Patient Educ Couns.* 2019;102:1957-1960.
 93. Knoerl R, Mazzola E, Hong F, et al. Exploring the impact of a decision support algorithm to improve clinicians' chemotherapy-induced peripheral neuropathy assessment and management practices: a two-phase, longitudinal study. *BMC Cancer.* 2021;21:236.
 94. Aapro M, Scotté F, Escobar Y, et al. Practice patterns for prevention of chemotherapy-induced nausea and vomiting and antiemetic guideline adherence based on real-world prescribing data. *Oncologist.* 2021;26:e1073-e1082.
 95. Henselmans I, van Laarhoven HWM, van Maarschalkerweerd P, et al. Effect of a skills training for oncologists and a patient communication aid on shared decision making about palliative systemic treatment: a randomized clinical trial. *Oncologist.* 2020;25:e578-e588.
 96. Eicher M, Ribí K, Senn-Dubey C, Senn S, Ballabeni P, Betticher D. Interprofessional, psycho-social intervention to facilitate resilience and reduce supportive care needs for patients with cancer: Results of a noncomparative, randomized phase II trial. *Psychooncology.* 2018;27:1833-1839.
 97. Yennurajalingam S, Rodrigues LF, Shamieh OM, et al. Decisional control preferences among patients with advanced cancer: An international multicenter cross-sectional survey. *Palliat Med.* 2018;32:870-880.
 98. Blum D, Seiler A, Schmidt E, Pavic M, Strasser F. Patterns of integrating palliative care into standard oncology in an early ESMO designated center: a 10-year experience. *ESMO Open.* 2021;6:100147.
 99. Ohta R, Ryu Y, Yoshimura M. Realist evaluation of interprofessional education in primary care through transprofessional role play: what primary care professionals learn together. *Educ Prim Care.* 2021;32:91-99.