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SYSTEMATIC REVIEW

Measuring the Socioeconomic Impact of Cancer: A Systematic Review and Standardized Assessment of Patient-Reported Outcomes (PRO) Instruments

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Abstract

Background A number of instruments have been developed to measure the socioeconomic impact (SEI) of cancer. A standardized comparison of the quality and content validity of these instruments is lacking. This study aimed to (1) conduct a standardized assessment of the quality of SEI instruments and (2) assess the content validity of these instruments using the conceptual framework developed by the Organization of European Cancer Institutes (OECI) for SEI analysis.

Method We identified articles measuring the SEI of cancer with ad hoc and/or validated instruments from an existing database. These articles were the initial pearls in a systematic review of published articles that applied and validated these instruments using the pearl-growing search strategy in PubMed, Web of Science, and Google Scholar databases. The Evaluating the Measurement of Patient-Reported Outcomes (EMPRO) tool was utilized to provide quantitative assessment and comparison of the quality of identified instruments. To examine content validity, we allocated each instrument's items against the themes and sub-themes of the established conceptual framework for SEI analysis.

Results We identified and investigated 21 validation studies using nine original instruments. The number of articles varied significantly among the identified instruments. The COmprehensive Score for financial Toxicity (COST) instrument was the most frequently used, validated in ten different settings, whereas some newer instruments have not been applied yet. This variation resulted in significant differences in EMPRO overall scores among these instruments. Regarding content validity, we found that not all themes of the OECI framework were covered by the content of the instruments.

Conclusion The quality and the application of instruments measuring the SEI of cancer varied significantly. The content of the instruments seems not to cover all related themes of the applied OECI framework in this study. Further studies are warranted to confirm the quality and content validity of the instruments measuring the SEI of cancer.

1 Introduction/Background

The socioeconomic impact (SEI) of cancer on patients and their families has been a subject of interest, reflected by a recent increase in publications [1]. Most studies have primarily focused on out-of-pocket (OOP) expenses as the primary cause of SEI [2]. However, in recent years, there has been a shift towards examining the broader consequences of these costs, encompassing psychological impacts and coping strategies for both cancer patients and their families. For instance, financial constraints might influence health-related decisions, causing some patients to delay or forgo necessary care. Other behavioral adjustments include using savings, selling assets, or taking loans to manage cancer-related expenses. Others might reduce spending by moving to more affordable housing, limiting food purchases, or eating less healthy, or cutting back on buying new clothing even when facing physical changes such as weight loss [2–5]. These dimensions have recently been integrated into a conceptual

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Key Points for Decision Makers

A standardized comparison of the quality and content validity of instruments measuring the socioeconomic impact (SEI) of cancer is lacking, underscoring a need for consistency in SEI measurement.

The Organization of European Cancer Institutes (OECI) framework provides a comprehensive, policy-relevant foundation for assessing SEI, addressing the impact of cancer on patients and their families.

Using the Evaluating the Measurement of Patient-Reported Outcomes (EMPRO) tool to assess quality, we found significant variation in the quality and use of current SEI instruments. Furthermore, content validity analysis revealed that existing SEI instruments do not comprehensively cover all domains of the OECI framework, leaving aspects of SEI unaddressed.

This study illuminates the need for future research and instrument validation aligned with a clear framework to comprehensively measure the SEI of cancer.

framework and taxonomy developed by the Organization of European Cancer Institutes (OECI) Task Force on the SEI analysis of cancer and cancer care [1], which functions as a guide for further research in the field (see Fig. 1).

The majority of studies examining the broader consequences of SEI developed their own questions, while a smaller number used pre-existing instruments. Some established instruments include the COmprehensive Score for financial Toxicity (COST) developed in the United States (US) [6, 7], the Financial Index of Toxicity (FIT) developed in Canada [8], and more recently, the Patient-Reported Outcome for Fighting Financial Toxicity (PROFFIT) developed in Italy [9]. However, these tools have limitations, such as a lack of validation for certain cancer types [10]. Other studies have utilized items from instruments that are primarily intended to measure concepts other than the SEI of cancer, such as quality of life (e.g., EORTC QLQ-C30) [11–13]. As we have argued previously [1], the SEI of cancer could be considered as a supplementary element but should remain distinct from health-related quality of life.

In this regard, there is a need for a validated and widely accepted patient-reported outcome (PRO) instrument to effectively capture dimensions of the SEI of cancer among patients and their families. A PRO is defined as 'any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else' [14]. A dedicated PRO instrument tailored for the SEI of cancer could be used to initially assess the level of impact on

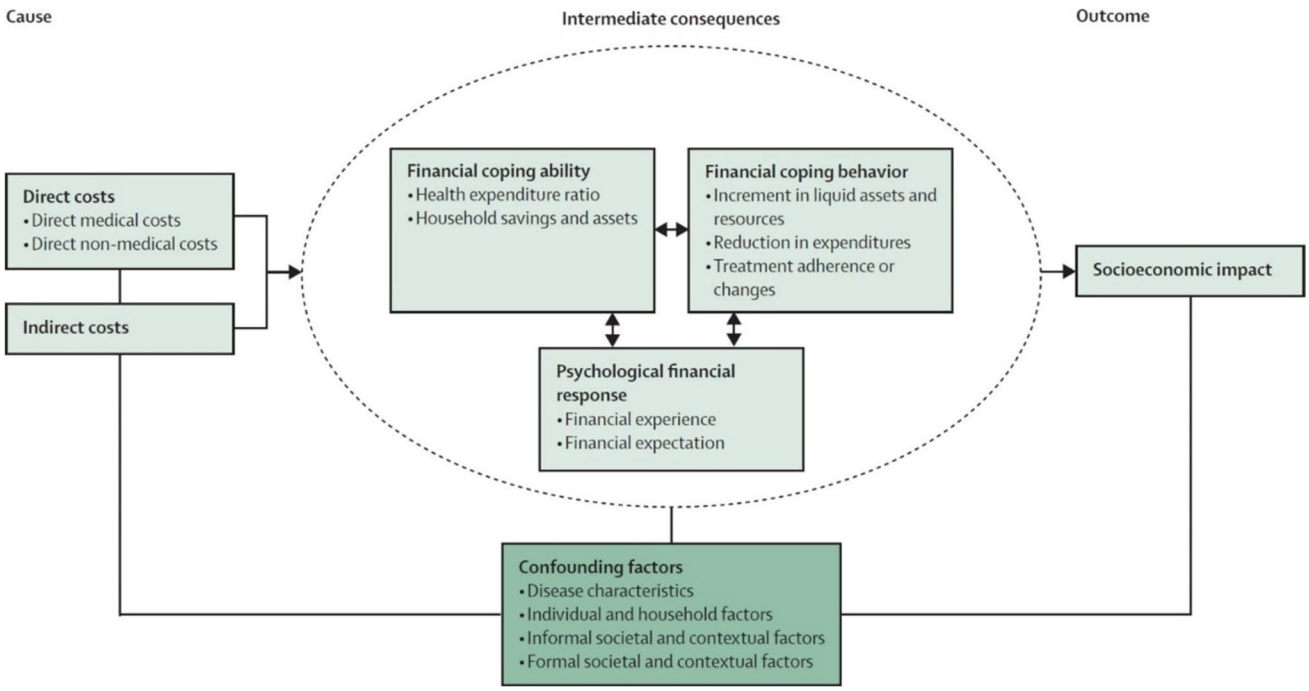

Fig. 1 Conceptual framework for socioeconomic impact analysis (adapted from Schlander et al., 2024 [1])

patients and their relatives, and further to measure outcomes that theoretically change (or remain static) when interventions are implemented to mitigate the SEI of cancer. Such a PRO instrument would serve as a valuable tool to guide policymakers.

The objective of this review is to assess the content validity of existing instruments and whether any of them can be qualified as widely accepted PRO measures for evaluating the SEI of cancer. The instruments mentioned—COST, FIT, and PROFFIT—have emerged to address this need. A systematic review of the validation, applicability, and reliability of these instruments will facilitate researchers to adapt the most appropriate instrument for their research question. Additionally, their adaptability to populations beyond their original intended use remains unexamined. There is limited comparative analysis among these instruments and other questionnaires, as well as a lack of evaluation regarding the strengths and weaknesses of the currently used questionnaires. To our knowledge, two existing studies by Zhu et al. [10] and Thomy et al. [15] have conducted a quality appraisal of available instruments measuring the SEI of cancer using the COSMIN criteria. However, the absence of a quantitative rating in the COSMIN tool may hinder effective comparison of the included instruments' quality. Additionally, a comparison of the content of instruments with a comprehensive framework is also yet to be conducted. Such a comparison would provide useful information regarding the concepts that each instrument measures, which would facilitate the choice of instruments in light of a research question in future studies.

In building upon our prior research efforts, particularly the recommendations and conceptual framework outlined in Schlander et al. [1] and Pham et al. [2], we further examined the extent to which current SEI instruments comprehensively capture the concept of cancer-related SEI on patients. We utilized the Evaluating the Measurement of Patient-Reported Outcomes (EMPRO) tool [16] to provide quantitative evidence and to clarify what additional information is needed in future validation and/or application studies of the PRO instruments measuring the SEI of cancer.

2 Methods

2.1 Search Strategy and Eligibility Criteria

2.1.1 Identification of the Instruments and Their Key Validation/Development/Application Studies

In this study, we focused on instruments specifically designed to measure only the construct of the SEI of cancer. Thus, instruments assessing SEI alongside other constructs (e.g., symptoms, overall health-related quality of life) were excluded. To identify relevant instruments, we used an existing database [17] maintained and annually updated at the Division of Health Economics, German Cancer Research Center (more details in Supplementary Material 1, see the electronic supplementary material). Relevant studies were identified in three steps: (1) identifying original research articles that addressed the financial coping ability, psychological impact, and coping behavior relevant to the SEI of cancer, as defined by the taxonomy recommendations of the OECI [1]; (2) discerning the types of questionnaires used in these articles (whether self-developed questionnaires or existing instruments were used); and (3) choosing instruments designed specifically for measuring SEI.

2.1.2 Pearl Growing

Relevant articles were grouped according to the instrument used. To enhance the search, we applied the pearl-growing strategy (also referred to as bidirectional citation searching [18] or snowballing [19]) for two reasons. First, the heterogeneous terminology in SEI research (e.g., financial toxicity, financial stress, economic impact, financial strain) complicates the creation of standardized search terms [1]. Second, we built upon previous systematic searches on financial burden (see Supplementary Material 1 in the electronic supplementary material) [17] to avoid redundancy and to explore the topic in greater depth.

To identify key articles ('pearls'), we compiled a comprehensive list of all references from each instrument group's bibliography and tallied the citation frequency. The most frequently cited reference in each group was examined in detail. If this article was related to the development and/or the validation of the targeted instrument, it was considered a pearl. If not, the second most cited reference was examined, and this process continued until a pearl was identified. When multiple articles equally fulfilled these criteria (i.e., multiple articles with an equal number of citations and being related to the development/validation of an instrument), all were taken as pearls, and their combined citations were included.

After identifying the pearl for each instrument, an additional systematic search was conducted in three databases: PubMed, Web of Science, and Google Scholar. For each instrument, the following steps were conducted:

Step 1: The pearl was identified in each database.

Step 2: All articles that cited the pearl were saved in each database and were combined into one list. In this list, each article contained the following information: title, author, journal, publication year, abstract and type of publication (*list 1*).

Step 3: Titles and abstracts of identified records were screened with the following exclusion criteria: (1) duplication; (2) publication year prior to the development of the

instrument; (3) the title was not written in English; (4) the title was missing; (5) type of publication: not an original research article (we refer to original research articles as studies that report in detail new work and are classified as primary literature according to Taylor & Francis Group [20]; consequently, we excluded books and book chapters, dissertations, reviews [systematic, scoping, rapid, expert reviews], conceptual model development, commentary and opinions [expert opinion, commentary on specific topic], reports, and policy recommendation); (6) qualitative studies; (7) conference abstracts; (8) study protocols; (9) studies not focused exclusively on cancer; (10) studies that did not use the particular instrument under our consideration, whether due to using self-developed surveys or omitting mention of the specific instrument among those used in their study (another example is studies that only report the monetary cost of cancer but did not report any score from an instrument); and (11) studies with databases that did not include any SEI instrument (these include the NCI Community Oncology Research Program (NCORP) 2017 Landscape Assessment Survey; Detroit Research on Cancer Survivors Cohort; Medical Expenditure Panel Survey; and National Health Interview Survey).

Step 4: The full-text of remaining records were screened independently by two reviewers (PDP and JU). At this stage, only those studies that applied, validated, or adapted a relevant instrument were included. All the references of included studies after this step were collected to create *list 2*.

Step 5: List 2 (from step 4) and *list 1* (from step 2) were compared, and all duplicate records were excluded. The new list should contain only new records that have not been screened yet.

Step 6: Steps 3 to 5 were repeated until no new records were identified. The number of repeated waves was reported for each instrument.

Step 7: All records throughout the process after screening were included in the *final list*. The records in this final list were read and grouped into packages for the quality appraisal process.

This whole process was repeated for newly identified instruments during the aforementioned pearl-growing steps. Moreover, systematic literature reviews were retained to capture cross-references of new instruments up to the day of database search, which was 28 September 2022. The flow of our process is illustrated in a Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) chart (see Fig. 2 and Supplemental Material 2).

2.2 Standardized Assessment Using EMPRO Tool

Two appraisers (PDP and JU) utilized the EMPRO tool [16] to perform a standardized assessment of the identified instruments. EMPRO comprises 39 items across eight attributes: conceptual and measurement model (i.e., the rationale for concepts and target populations), reliability (internal consistency and reproducibility), validity, responsiveness, interpretability, burden, alternative modes of administration, and cross-cultural and linguistic adaptations [16]. In its pilot test, EMPRO demonstrated strong reliability and validity using measures such as the SF-36 Health Survey, EuroQol-5D, and Quality of Life Questionnaire EORTC-QLQ-C30 [16].

The appraisers, rated their degree of agreement on a four-point scale, ranging from 4 (‘strongly agree’) to 1 (‘strongly disagree’), with options for 'no information available' and ‘not applicable’ when needed. The appraisers provided detailed comments to explain their ratings. Instruments applied or validated in different contexts were treated as distinct versions and evaluated separately. Discrepancies were reconciled to achieve consensus.

Following EMPRO guidelines, attribute scores were computed as the mean of responses for each attribute, transformed to a 0 to 100 scale. The overall score was calculated based on the concept, validity, reliability, responsiveness, and interpretability attributes for each instrument. For the ‘reliability’ attribute in particular, sub-attributes including ‘internal consistency’ and ‘reproducibility’ were assessed, with the higher scoring sub-attribute determining the attribute score. Detailed information and algorithms for calculating EMPRO scores are available from the authors of the EMPRO tool via the Patient-Reported Outcome International Online Library website (biblioPRO.org).

2.3 Concepts Reflected by the Items of Included Instruments

To study the concepts that were reflected by the instruments, we allocated each item of the instruments to the themes and sub-themes of the established conceptual framework for SEI analysis (see Fig. 1) [1]. The applied framework was developed by OECI, which aimed to fill the gap in standards and guidance for studies exploring the SEI of cancer and cancer care on patients and their relatives [1]. This framework of SEI consists of various themes, sub-themes, and their relationships [1]. Our allocation process was conducted independently by three researchers (JU, RE, and PDP), who are familiar with PRO development and validation, and participated in the development of the applied SEI conceptual framework. Items could be allocated to multiple themes and

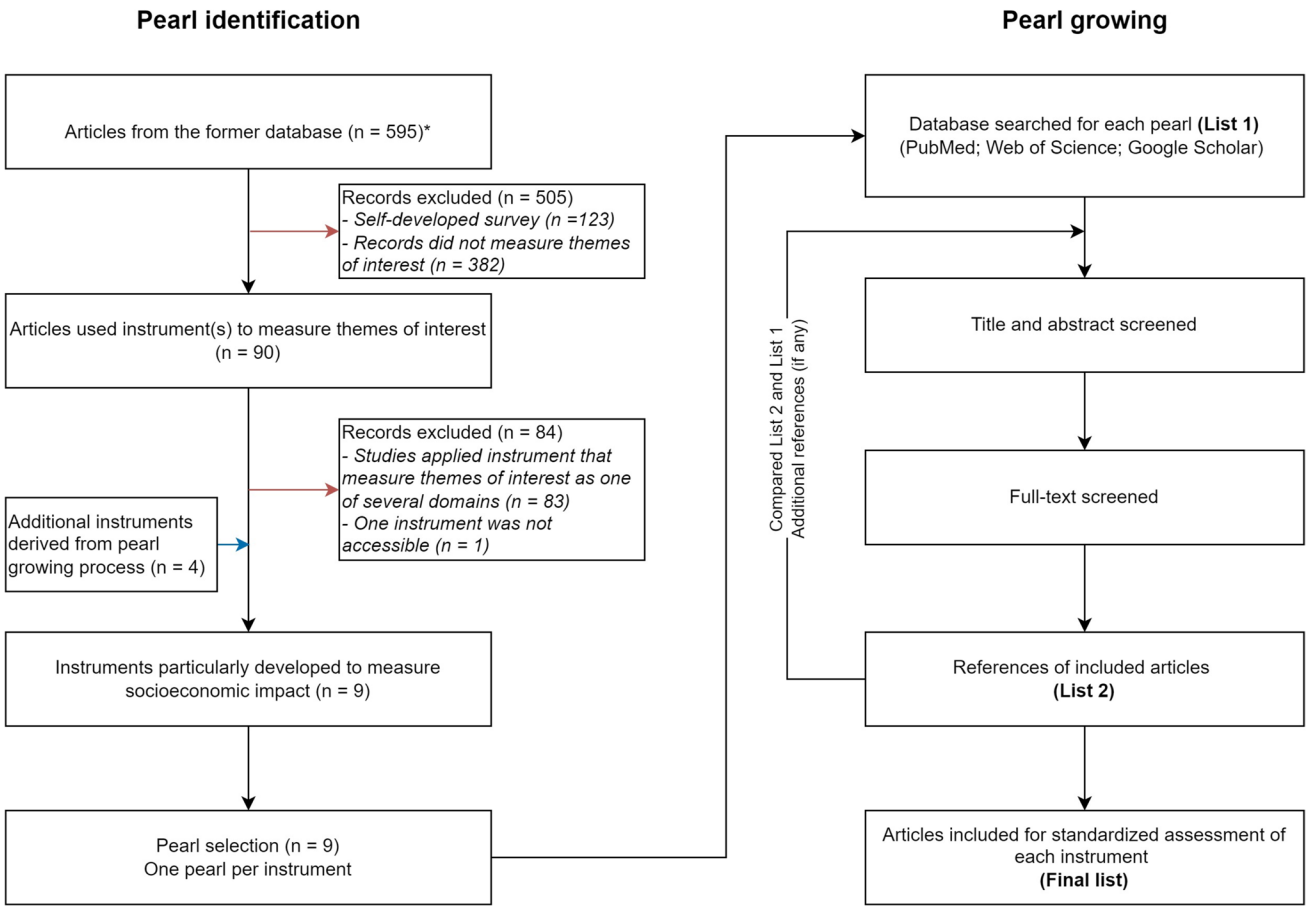

Fig. 2 PRISMA chart – pearl selection and overall pearl-growing search process. *PRISMA* Preferred Reporting Items for Systematic reviews and Meta-Analyses. *See Supplemental Material 1 for more details

subthemes, or not allocated to any when they reflected a different concept altogether.

After assigning items, JU, RE, and PDP compared and discussed their allocations to reach consensus on each item's placement within the OECI conceptual framework. These results were then used to analyze which concepts each instrument covered (see Table 2).

3 Results

3.1 Pearl Identification

Figure 2 depicts the pearl selection and overall pearl-growing process. Out of 595 records, six instruments [7, 8, 21–24] were identified in the database from the Division of Health Economics [17], while four additional instruments [9, 25–27] were identified through the pearl-growing process. One instrument [22] remained inaccessible despite attempts to contact the authors, resulting in nine instruments being included in this study.

Nine studies were utilized as initial pearls for the nine included instruments. Each study is associated with a unique instrument: the COST [7], the Economic Hardship Questionnaire (EHQ) [21], the FIT [8], the InCharge Financial Distress/Financial Well-being (IFDFW) [24], the Socioeconomic Well-being Scale (SWBS) [23], the Personal Financial Burden (PFB) [27], the PROFFIT [9], the Hardship And Recovery with Distress Survey (HARDS) [26], and the Subjective Financial Distress Questionnaire (SFDQ) [25].

3.2 Pearl Growing

The pearl-growing process was conducted for each of the included instruments. For the COST instrument, from 561 articles citing the pearl in three databases, we identified 69 articles (development, validation, and application studies using the COST instrument) to be eligible for standardized assessment (see Supplementary Material 2 in the electronic supplementary material). The detailed PRISMA charts for each instrument are illustrated in Supplementary Material 2.

Table 1 provides a summary of the descriptive characteristics of the pearls and their respective instruments. All nine instruments were developed after 2001, with four instruments developed within the last 3 years: the SFDQ [25], the HARDS [26], the FIT [8], and the PROFFIT [9]. The majority of these instruments (5 out of 9) were originally validated in the US [6, 7, 21, 23, 24, 27]. The four remaining instruments were validated in four other countries: the FIT in Canada [8], the PROFFIT in Italy [9], the SFDQ in India [25], and the HARDS in China [26]. Seven instruments were specifically validated among cancer populations (SFDQ, HARDS, FIT, PROFFIT, COST, SWBS, and PFB), whereas two were validated in non-cancer populations (EHQ, IFDFW). Notably, the EHQ was validated in parents of seventh- or eighth-grade children without cancer. The number of items in each instrument ranged from seven (PFB and PROFFIT) to 20 (EHQ).

The COST instrument was the most commonly used instrument to assess the SEI of cancer and was applied in 57 studies. Although not cancer specific, the IFDFW [24] and the EHQ [21] were the second ($n = 15$) and third ($n = 6$) most frequently used instruments (after COST) for measuring the SEI of cancer, as shown in Table 1. The three newly developed instruments (the FIT [8], the SFDQ [28], and the HARDS [26]) have yet to be applied or validated in other studies at the time of the current review.

Only two instruments, the COST and the IFDFW, were utilized in other countries beyond where they were originally developed (hereby, referred to as contextually adapted versions). Apart from the US, the COST [7] was applied and/or validated in various linguistic versions in multiple countries including India [28], Brazil [29], China [30, 31], Australia [32], Italy [33], Iran [34], Japan [35], and Tunisia [36]. The IFDFW was applied in Iran and Malaysia in Persian and Malaysian versions, respectively.

Further details pertaining to individual instruments can be found in Supplementary Material 2.

3.3 Standardized Assessment

Twenty-one validation studies were conducted for the nine originally developed instruments, ten contextually adapted versions of the COST, and two contextually adapted versions of the IFDFW. Among the adaptations of the COST, six validated the 11-item original COST version 1 (COST V1) developed by de Souza et al. (2014) [6], while four validated the 12-item COST version 2 (COST V2) released by the FACIT group [37]. The overall EMPRO and their attributable-specific scores for each instrument are illustrated in Fig. 3.

Regarding the 'concept and measurement model' attribute of the EMPRO tool, the nine original instruments provided sufficient information for attribute scoring (refer to Supplementary Material 3; see the electronic supplementary material). Scores ranged from 19.05 (PFB) to 90.47 (COST), with six original instruments scoring over 50: the COST (90.47), the PROFFIT (71.43), the EHQ (57.14), the IFDFW (52.38), the SFDQ (52.38), and the HARDS (52.38). This attribute contributed considerably to the overall EMPRO score of these instruments, as shown in Fig. 3. In contrast, the contextual adaptations of the COST and the IFDFW lacked sufficient information for scoring in this attribute, as they assumed the generalizability of the original instruments' concept and measurement model to different cultural and linguistic settings.

Most instruments' 'reliability' scores were derived from the 'internal consistency' sub-attribute due to low reproducibility scores or lack of available information (refer to Supplementary Material 3). Four original instruments scored over 50 for reliability: the SWBS (77.78), the COST (75), the EHQ (58.33), and the PROFFIT (55.56). Among the contextual adaptations, six versions scored 55.56, and the rest either scored below 50 or were not scorable due to insufficient information. 'Reliability' is the most popular attribute having a score ($n = 16$) among the 21 investigating validation studies (refer to Fig. 3).

For the 'validity' attribute, the SFDQ and the HARDS lacked information for scoring. Among the remaining seven original instruments, scores ranged from 33.33 to 100. The COST achieved the highest score (100), followed by the IFDFW (66.67) (refer to Supplementary Material 3). Among contextual adaptations, only two versions of the COST scored 50 and 58.33, while the rest were non-scorable due to limited information available.

Very limited information was identified for the 'responsiveness,' 'interpretability,' 'burden,' and 'alternative modes of administration' attributes, rendering most instruments non-scorable in these aspects, significantly influencing the overall EMPRO score. Consequently, only the original COST instrument attained a score above 50 (66.42), while contextual adaptations of the COST scored below 50 due to insufficient information (refer to Fig. 3 and Supplementary Material 3).

3.4 Concepts Reflected by the Included Instruments

Table 2 summarizes our allocation of each item of the included instruments to the themes and subthemes of the OECI conceptual framework [1]. The theme most frequently assessed by the instruments was 'financial coping ability' (all nine instruments), followed by 'psychological financial response' (eight instruments, except the PFB), and 'financial coping behavior' (7 instruments, except the COST and the SWBS).

Only one instrument (the PROFFIT) addressed the theme of 'direct costs' by considering the 'non-medical costs' of

Table 1 Descriptive statistics of the pearls – key publications of included instruments

Authors	Pearl title (instrument abbreviation)	Cancer specific	Context of validation	Original population of validation study	Sample size of validation study	No. of items	Score range	No. of papers applying instrument	No. of papers validating instrument	Other applications/validation contexts
Barrera et al., 2001 [21]	The Psychological Sense of Economic Hardship: Measurement Models, Validity, and Cross-Ethnic Equivalence for Urban Families (EHQ)	No	USA	Participants were the parents of 319 seventh or eighth graders	194 fathers and 319 mothers	20	Not specified	6	1	Not available
Dar et al., 2021 [25]	Development and Validation of Subjective Financial Distress Questionnaire: A Patient Reported Outcome Measure for Assessment of Financial Toxicity Among Radiation Oncology Patients (SFDQ)	Yes	India	Head and neck cancer patients age ≥ 18 years	150 patients	14	0–28	0	1	Not available
de Souza et al., 2017 [7]	Measuring Financial Toxicity as a Clinically Relevant Patient-Reported Outcome: The Validation of the COmprehensive Score for financial Toxicity (COST)	Yes	USA	Patients ≥ 18 years with AJCC stage IV solid tumors receiving chemotherapy for at least 2 months	233 patients	11	0–44	57	12	India, Brazil, China, Australia, Italy, Iran, Japan, Tunisia

Table 1 (continued)

Authors	Pearl title (instrument abbreviation)	Cancer specific	Context of validation	Original population of validation study	Sample size of validation study	No. of items	Score range	No. of papers applying instrument	No. of papers validating instrument	Other applications/validation contexts
Head, 2007 [23]	Development and validation of a scale to measure health-related socioeconomic well-being in persons with a cancer diagnosis (SWBS)	Yes	USA	Cancer survivors listed on the Tumor Registry as being diagnosed with cancer between January 2004 and December 2005	266 cancer survivors	17	Generated as part of the quality-of-life questionnaire	1	1	Not available
Hueniken et al., 2020 [8]	Measuring Financial Toxicity Incurred After Treatment of Head and Neck Cancer: Development and Validation of the Financial Index of Toxicity Questionnaire (FIT)	Yes	Canada	Patients with head and neck cancer at 12 to 24 months after treatment	430 patients	9	0–100	0	1	Not available
Liu et al., 2023 [26]	The development and validation of a patient-reported outcome measure to assess financial hardship among older cancer survivors in China: Hardship and Recovery with Distress Survey (HARDS)	Yes	China	Old adults (> 60 years) with cancer	518 patients	10	10–50	0	1	Not available

Table 1 (continued)

Authors	Pearl title (instrument abbreviation)	Cancer specific	Context of validation	Original population of validation study	Sample size of validation study	No. of items	Score range	No. of papers applying instrument	No. of papers validating instrument	Other applications/validation contexts
Prawitz et al., 2006 [24]	The InCharge Financial Distress/Financial Well-being Scale: Establishing Validity and Reliability (IFDFW)	No	USA	Using 2004 data from the financially distressed sample of credit counseling clients and the general population	590 credit counseling clients and 1097 general population	8	8–80	15	1	Iran, Malaysia
Riva et al., 2021 [9]	Cross-sectional study to develop and describe psychometric characteristics of a patient-reported instrument for measuring financial toxicity of cancer within a public healthcare system (PROFFIT)	Yes	Italy	(1) Adult patients (> 18 years), (2) histologically or cytologically confirmed diagnosis of any type of solid cancer or hematological malignancy, (3) medical treatment (chemotherapy, target agents, immunotherapy, hormonal treatment, radiotherapy, or combinations of such therapies) ongoing or terminated within the previous 3 months	184 patients	7	Not specified	1	1	Not available

Table 1 (continued)

Authors	Pearl title (instrument abbreviation)	Cancer specific	Context of validation	Original population of validation study	Sample size of validation study	No. of items	Score range	No. of papers applying instrument	No. of papers validating instrument	Other applications/validation contexts
Veenstra et al., 2014 [27]	A Composite Measure of Personal Financial Burden Among Patients with Stage III Colorectal Cancer (PFB)	Yes	USA	Colorectal cancer patients	956 patients	7	0–6 for financial burden and 1–5 for worry	3	1	Not available

AJCC American Joint Committee on Cancer, *COST* COmprehensive Score for financial Toxicity, *EHQ* Economic Hardship Questionnaire, *FIT* Financial Index of Toxicity, *HARDS* Hardship And Recovery with Distress Survey, *IFDFW* InCharge Financial Distress/Financial Well-being, *PFB* Personal Financial Burden, *PROFFIT* Patient-Reported Outcome for Fighting Financial Toxicity, *SFDQ* Subjective Financial Distress Questionnaire, *SWBS* Socioeconomic Well-being Scale

travel for treatment, without quantifying the amount in monetary terms. Similarly, only three out of nine instruments addressed the 'indirect costs' theme, including the COST, the FIT, and the SFDQ.

Based on our allocation process, two instruments covered most of the themes of the framework, namely the PROFFIT [9] and the SFDQ [25]. The PROFFIT instrument covered all the themes, except for 'indirect costs,' whereas the SFDQ instrument covered all themes of the framework except for 'direct costs.' Accordingly, none of the included instruments covered all the themes of the framework.

4 Discussion

We systematically identified and assessed nine original PRO measures (i.e., the COST, EHQ, FIT, HARDS, IFDFW, PFB, PROFFIT, SFDQ, and SWBS instruments) and 12 contextually adapted versions of the COST and IFDFW instruments (i.e., the COST V1 China, COST V2 China, COST V1 Australia, COST V2 Italy, COST V1 Iran, COST V2 Turkey, COST V1 India, COST V2 Brazil, COST V1 Japan, COST V1 Tunisia, IFDFW Iran, and IFDFW Malaysia instruments) measuring the SEI of cancer. To the best of our knowledge, this is the first study using the EMPRO tool [16] to assess and score the properties of instruments measuring the SEI of cancer.

In our standardized assessment, the original COST instrument [6, 7] received the highest rating, scoring 66.42 out of 100. It was the only instrument to surpass the 50-point threshold in the US context, which is considered to be 'reasonably acceptable' according to the authors of the EMPRO tool [16]. This instrument also scored the highest in several attributes, including 'conceptual and measurement model,' 'reliability,' 'validity,' and 'responsiveness.' However, the applicability of the COST instrument outside the US remains unclear due to insufficient data on the validity when used in other countries. We lacked enough information to provide attribute-specific scores for the ten contextually adapted versions of COST that we identified (see Supplementary Material 3 in the electronic supplementary material). This gap echoes findings from a systematic review by Zhu et al. (2022) on the psychometric properties of financial toxicity instruments [10]. They recommended that future validation studies of the COST instrument should account for diverse social and cultural backgrounds to evaluate its broader applicability.

Another instrument, the IFDFW [24], which was developed in the US, has been applied internationally. It received the second highest overall EMPRO score of 39.37, which is somewhat short of the 50-point threshold considered only 'reasonably acceptable.' Moreover, this instrument was originally validated among the general US population and is not

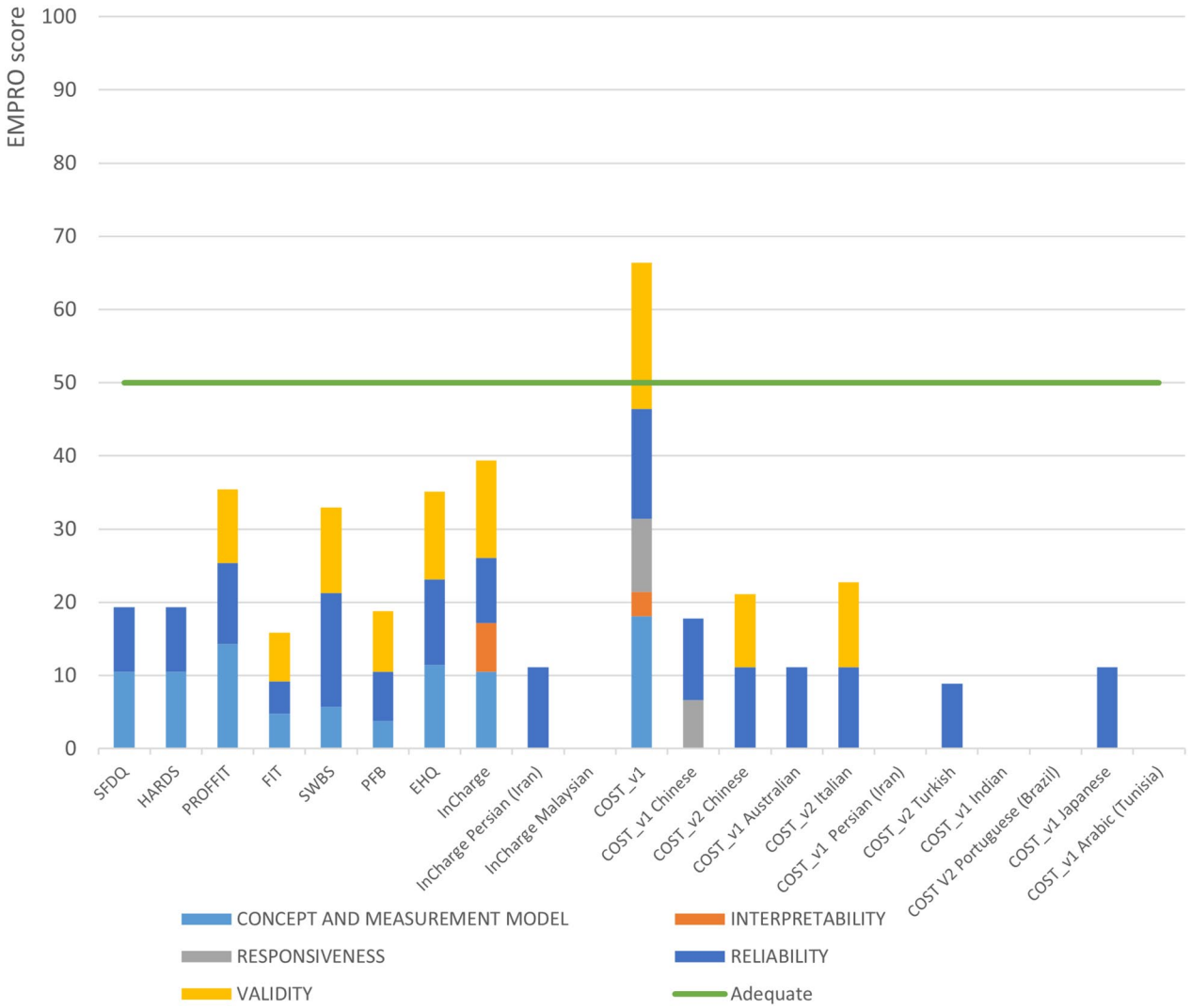

Fig. 3 The overall EMPRO and attributable scores of included instruments. Instruments with no score: Unable to score due to unavailable/limited information. *COST* COmprehensive Score for financial Toxicity, *EHQ* Economic Hardship Questionnaire, *EMPRO* Evaluating the Measurement of Patient-Reported Outcomes, *FIT* Financial Index of Toxicity, *HARDS* Hardship And Recovery with Distress Survey, *InCharge* InCharge Financial Distress/Financial Well-being (IFDFW), *PFB* Personal Financial Burden, *PROFFIT* Patient-Reported Outcome for Fighting Financial Toxicity, *SFDQ* Subjective Financial Distress Questionnaire, *SWBS* Socioeconomic Well-being Scale, *v* version

cancer specific [24]. Despite this, it has been applied in 15 cancer-related studies: 13 in the US, one in Iran, and one in Malaysia. However, there was insufficient information to calculate attribute-specific EMPRO scores for the latter two versions. Further studies are needed to establish the validity of the IFDFW both in general and in other contexts.

Among the remaining instruments, several were originally developed outside the US, including PROFFIT in Italy, HARDS in China, SFDQ in India, and FIT in Canada. Our standardized assessment using the EMPRO tool identified PROFFIT as a promising instrument potentially applicable not only in the original Italian context but also in other countries with similar health systems. However, further validation studies are necessary to ensure the reliability and validity of this instrument in these new contexts. This recommendation is consistent with that of Zhu et al. [10].

Although the nine original instruments provided sufficient evidence to score the 'concept and measurement model' attribute, information pertaining to their conceptual frameworks was limited. For some instruments, the process of developing conceptual models involved direct engagement with the target population, namely, cancer patients [6, 9, 25]. However, the conceptual models—when they existed—were not informed by broader conceptual insights from health economic costing theory, nor did they fully capture the specific experiences of patients included in qualitative studies.

Table 2 Item allocation to the OECI conceptual framework

Instrument name	Capturing concept(s) (according to the authors)	Item	Relevant sub-theme(s) covered	Relevant theme(s) covered	Other themes not covered by the instrument
COmprehensive Score for financial Toxicity (COST)	Financial toxicity	I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment	Household savings and assets	Financial coping ability	*Direct costs, Financial coping behavior, Confounding factors*
		My out-of-pocket expenses are more than I thought they would be	Financial experience, Financial expectation, Health expenditure ratio	Psychological financial response, Financial coping ability	
		I worry about the financial problems I will have in the future as a result of my illness or treatment	Financial expectation	Psychological financial response	
		I feel I have no choice about the amount of money I spend on care	Financial experience, Financial expectation	Psychological financial response; Financial coping ability	
		I am frustrated that I cannot work or contribute as much as I usually do	Financial experience, Financial expectation	Psychological financial response	
		I am satisfied with my current financial situation	Financial experience	Psychological financial response	
		I am able to meet my monthly expenses	Financial experience	Psychological financial response	
		I feel financially stressed		Psychological financial response	
		I am concerned about keeping my job and income, including work at home	Financial expectation, Health expenditure ratio	Psychological financial response, Financial coping ability, Indirect costs	
		My cancer or treatment has reduced my satisfaction with my present situation	Financial experience	Psychological financial response	
		I feel in control of my financial situation	Financial experience, Financial expectation	Psychological financial response	
InCharge - Financial Well-being Scale	Financial distress, financial well-being	What do you feel is the level of your financial stress today?	Financial experience	Psychological financial response	*Direct costs; Indirect costs; Confounding factors*
		On the stair steps below, mark how satisfied you are with your present financial situation	Financial experience	Psychological financial response	
		How do you feel about your current financial situation?	Financial experience	Psychological financial response	
		How often do you worry about being able to meet normal monthly living expenses?	Financial experience, Financial expectation	Psychological financial response	
		How confident are you that you could find the money to pay for a financial emergency that costs about $1000?	Household savings and assets, Health expenditure ratio, Increment in liquid assets and resources	Financial coping ability, Financial coping behavior	
		How often does this happen to you? You want to go out to eat, go to a movie, or do something else and don't go because you can't afford to?	Reduction in expenditures	Financial coping behavior	
		How frequently do you find yourself just getting by financially and living paycheck to paycheck?	Health expenditure ratio	Financial coping ability	
		How stressed do you feel about your personal finances in general?	Financial experience	Psychological financial response	

Table 2 (continued)

Instrument name	Capturing concept(s) (according to the authors)	Item	Relevant sub-theme(s) covered	Relevant theme(s) covered	Other themes not covered by the instrument
Financial Index of Toxicity (FIT)	Financial toxicity	During the past year, were you satisfied with your family's financial situation?	Financial experience	Psychological financial response	*Direct costs, Confounding factors*
		During the past year, were you worried about your family's financial situation?	Financial experience	Psychological financial response	
		How did you perceive your family's financial situation compared to others of the same age?	Financial experience, Financial expectation	Psychological financial response	
		During the past year, were you able to pay for your daily food expenses?	Health expenditure ratio	Financial coping ability, Financial coping behavior	
		During the past year, were you able to pay for your daily housing expenses?	Reduction in expenditures	Financial coping behavior	
		During the past year, were you able to pay for your medications related to your treatment?	Treatment adherence/changes	Financial coping behavior	
		During the past year, did you have to borrow money to help with treatment-related expenses from family/friends/financial institutions?	Increment in liquid assets and resources	Financial coping behavior	
		Have you had to permanently quit your previous occupation because of your cancer diagnosis and/or treatment?		Indirect costs	
		Did any of your family or friends have to permanently quit their job to help with your care needs because of your cancer diagnosis or treatment?		Indirect costs	

Table 2 (continued)

Instrument name	Capturing concept(s) (according to the authors)	Item	Relevant sub-theme(s) covered	Relevant theme(s) covered	Other themes not covered by the instrument
Socioeconomic Well-being Scale (SWBS)	Socioeconomic well-being	I am able to make enough money to pay for my healthcare	Health expenditure ratio	Financial coping ability	*Direct costs; Indirect costs; Financial coping behavior*
		I know how to get the healthcare services I need	Psychological financial response (Financial experience)	Confounding factors	
		I understand the healthcare system		Confounding factors	
		I have to pay more for my medical care than I can afford		Psychological financial response	
		I am able to pay my medical bills		Psychological financial response	
		I believe that being sick will hurt me financially	Financial expectation	Psychological financial response	
		I have enough money to take care of my healthcare needs	Household savings and assets, Health expenditure ratio	Financial coping ability	
		I can afford my medical check-ups even when I am not sick	Health expenditure ratio, Household savings and assets	Financial coping ability	
		I can get the health insurance I need	Health expenditure ratio	Financial coping ability	
		The medicine I need is too expensive for me	Health expenditure ratio	Financial coping ability	
		People like me are able to get the healthcare they need		Confounding factors	
		Healthcare services are easy to get in my neighborhood	Financial experience	Psychological financial response	
		I am treated the same as other patients when I go for medical care		Other construct - Satisfaction with care	
		People I know best have healthy habits	Financial experience	Psychological financial response	
		My family thinks good healthcare is important	Financial experience	Psychological financial response	
		I know people who will help me out when I'm sick		Confounding factors	
		I can easily get information about healthcare		Confounding factors	

Table 2 (continued)

Instrument name	Capturing concept(s) (according to the authors)	Item	Relevant sub-theme(s) covered	Relevant theme(s) covered	Other themes not covered by the instrument
Economic Hardship Questionnaire (EHQ)	Economic hardship	In the next 3 months, how often do you think that you and your family will experience bad times such as poor housing or not having enough food?	Reduction in expenditures	Financial coping behavior	*Direct costs; Indirect costs; Confounding factors*
		In the next 3 months, how often do you expect that you will have to do without the basic things that your family needs?	Financial expectation	Psychological financial response	
		Think back over the past 3 months and tell us how much difficulty you had with paying your bills?	Financial experience; Health expenditure ratio	Psychological financial response; Financial coping ability	
		Think again over the past 3 months. Generally, at the end of each month did you end up with … money left?	Health expenditure ratio	Financial coping ability	
		My family had enough money to afford the kind of home we should have	Financial experience; Household savings and assets	Psychological financial response; Financial coping ability	
		My family had enough money to afford the kind of clothing we should have	Financial experience; Reduction in expenditures	Psychological financial response; Financial coping behavior	
		My family had enough money to afford the kind of furniture or household appliances we should have	Financial experience; Reduction in expenditures	Psychological financial response; Financial coping behavior	
		My family had enough money to afford the kind of car we need	Financial experience; Household savings and assets, Reduction in expenditures	Psychological financial response; Financial coping ability; Financial coping behavior	
		My family had enough money to afford the kind of food we should have	Financial experience; Reduction in expenditures	Psychological financial response; Financial coping behavior	
		My family had enough money to afford the kind of medical care we should have	Financial experience; Treatment adherence/changes	Psychological financial response; Financial coping behavior	
		My family had enough money to afford leisure and recreational activities	Financial experience; Reduction in expenditures	Psychological financial response; Financial coping behavior	
		Changed food shopping or eating habits a lot to save money	Reduction in expenditures	Financial coping behavior	
		Shut down the heat or air conditioning to save money even though it made the house uncomfortable	Reduction in expenditures	Financial coping behavior	
		Didn't go to see the doctor or dentist when you needed to because you had to save money	Treatment adherence/changes	Financial coping behavior	
		Fell far behind in paying bills			
		Asked relatives or friends for money or food to help you get by	Increment in liquid assets and resources	Financial coping behavior	
		Added another job to make ends meet	Increment in liquid assets and resources	Financial coping behavior	
		Received government assistance	Increment in liquid assets and resources	Financial coping behavior	
		Sold some possessions because you needed the money (even though you really wanted to keep them)	Increment in liquid assets and resources	Financial coping behavior	
		Moved to another house or apartment to save some money	Reduction in expenditures	Financial coping behavior	

Table 2 (continued)

Instrument name	Capturing concept(s) (according to the authors)	Item	Relevant sub-theme(s) covered	Relevant theme(s) covered	Other themes not covered by the instrument
The Hardship And Recovery with Distress Survey (HARDS)	Subjective financial distress, objective medical burden	I was unable to cover the costs of my cancer care.	Financial experience; Health expenditure ratio	Psychological financial response; Financial coping ability	*Direct costs; Indirect costs; Confounding factors*
		I didn't have enough money in savings, retirement, or assets to cover the costs of my treatment.	Financial experience; Household savings and assets; Treatment adherence or changes	Psychological financial response; Financial coping ability; Financial coping behavior	
		I had no choice but to rely on my children to pay for medical costs.	Health expenditure ratio, Increment in liquid assets and resources	Financial coping behavior; Financial coping ability	
		I've had to borrow money or go into debt because of the costs of my cancer care.	Increment in liquid assets and resources	Financial coping behavior	
		The costs of my cancer care ate up my money.	Increment in liquid assets and resources; Health expenditure ratio; Household savings and assets	Financial coping behavior; Financial coping ability	
		I worried about my family's financial stability because of the costs of my cancer care.	Financial experience; Financial expectation	Psychological financial response	
		I worried about the loss of both my life and money in the future as a result of my cancer care.	Financial expectation	Psychological financial response	
		If medical costs are too much for my present financial situation, I would give up my treatment.	Treatment adherence/changes	Financial coping behavior	
		I have reduced spending on basics like food or clothing because of the costs of my cancer care.	Reduction in expenditures; Treatment adherence/changes	Financial coping behavior	
		I would choose the medications for my cancer care covered by my insurance.	Treatment adherence/changes	Financial coping behavior	
Personal Financial Burden (PFB)	Personal financial burden	I had to use savings	Increment in liquid assets and resources; Household savings and assets	Financial coping behavior, Financial coping ability	*Direct costs; Indirect costs; Psychological financial response; Confounding factors*
		I had to borrow money or take out a loan	Increment in liquid assets and resources	Financial coping behavior	
		I could not make payments on credit cards	Health expenditure ratio; Reduction in expenditures	Financial coping behavior, Financial coping ability	
		I cut down on spending for food/clothes	Reduction in expenditures	Financial coping behavior	
		I cut down spending for health care for others	Reduction in expenditures	Financial coping behavior	
		I cut down on recreational activities	Reduction in expenditures	Financial coping behavior	
		I cut down on expenses in general	Reduction in expenditures	Financial coping behavior	

Table 2 (continued)

Instrument name	Capturing concept(s) (according to the authors)	Item	Relevant sub-theme(s) covered	Relevant theme(s) covered	Other themes not covered by the instrument
Patient-Reported Outcome for Fighting Financial Toxicity (PROFFIT)	Financial toxicity	I can afford my monthly expenses without difficulty (e.g., rent, electricity, phone…)	Health expenditure ratio; Financial experience; Financial expectation	Financial coping ability; Psychological financial response	*Indirect costs*
		My illness has reduced my financial resources	Health expenditure ratio; Household savings and assets; Financial experience	Psychological financial response; Financial coping ability	
		I am concerned by the economic problems I may have in the future due to my illness	Financial expectation	Psychological financial response	
		My economic situation affects the possibility of receiving medical care	Health expenditure ratio, Treatment adherence/changes	Financial coping ability, Financial coping behavior	
		I have reduced my spending on leisure activities such as holidays, restaurants, or entertainment in order to cope with expenses related to my illness	Reduction in expenditures	Financial coping behavior	
		I have reduced spending on essential goods (e.g., food) in order to cope with expenses related to my illness	Reduction in expenditures	Financial coping behavior	
		I am worried that I will not be able to work due to my illness	Financial expectation; Financial experience	Psychological financial response	
		The National Health Service covers all health costs related to my illness	Formal societal and contextual factors; Treatment adherence or changes	Confounding factors, Financial coping behavior	
		I have paid for one or more private medical examinations for my illness	Formal societal and contextual factors; Treatment adherence or changes; Health expenditure ratio	Financial coping behavior, Financial coping ability, Confounding factors	
		I have paid for additional medicines or supplements related to my illness	Formal societal and contextual factors; Treatment adherence or changes	Confounding factors; Financial coping behavior	
		I have to pay for additional treatment myself (e.g., physiotherapy, psychotherapy, dental care)	Formal societal and contextual factors; Treatment adherence or changes	Confounding factors; Financial coping behavior	
		The treatment center is a long way from where I live	Formal contextual and societal factors	Confounding factors	
		I have spent a considerable amount of money on travel for treatment	Non-medical costs; Formal contextual and societal factors; Financial experience	Direct costs, Confounding factors, Psychological financial response	
		Medical staff (i.e., doctors, nurses, etc.) have been helpful throughout my medical care	Informal contextual and societal factors	Confounding factors	
		Staff in hospital administration (i.e., for booking appointments, secretaries, etc.) have been helpful throughout my medical care	Informal contextual and societal factors	Confounding factors	
		Medical staff and medical facilities I attended communicated with each other	Informal contextual and societal factors	Confounding factors	

Table 2 (continued)

Instrument name	Capturing concept(s) (according to the authors)	Item	Relevant sub-theme(s) covered	Relevant theme(s) covered	Other themes not covered by the instrument
Subjective Financial Distress Questionnaire (SFDQ)	Subjective financial distress	Do you have sufficient financial resources to cover costs related to your cancer treatment?	Financial experience; Household savings and assets, Health expenditure ratio	Psychological financial response; Financial coping ability	*Direct costs*
		Have you experienced a loss of income/employment/work as a result of your cancer diagnosis or treatment?	Financial experience	Psychological financial response; Indirect costs	
		Have you faced any difficulties in paying for cancer-related treatment costs?	Financial experience; Health expenditure ratio	Psychological financial response; Financial coping ability	
		Have you faced any difficulties in paying for treatment-related travel, food, and lodging expenses?	Financial experience; Health expenditure ratio	Psychological financial response; Financial coping ability	
		How much of financial burden has treatment-related out-of-pocket expenses been on you or your family?	Financial experience; Health expenditure ratio	Psychological financial response, Financial coping ability	
		Have you faced any difficulties in paying for daily household expenses due to cancer diagnosis/treatment?	Financial experience; Health expenditure ratio	Financial coping ability, Psychological financial response,	
		Are you currently in debt as a result of cancer-related treatment expenses?	Financial experience; Increment in liquid assets and resources; Health expenditure ratio, Household savings and assets	Psychological financial response; Financial coping ability; Financial coping behavior	
		Is your current financial condition satisfactory to you?	Financial experience	Psychological financial response	
		Have you or your family experienced financial hardship as a result of your cancer treatment?	Financial experience; Health expenditure ratio	Psychological financial response, Financial coping ability	
		Is your financial situation worsening as a result of your cancer diagnosis or treatment?	Health expenditure ratio; Financial experience; Financial expectation	Financial coping ability, Psychological financial response	
		Have you delayed or avoided treatment, follow-up, or a recommended procedure due to financial concerns?	Treatment adherence/changes	Financial coping behavior	
		Have you or your family cut back on essentials like food and clothing as a result of cancer-related expenses?	Reduction in expenditures	Financial coping behavior	
		Has the financial aid eased the distress due to cancer treatment on you and your family?	Formal societal and contextual factors/financial experience	Confounding factors/Psychological financial response	
		Have you discussed about the financial concerns of cancer treatment with your oncologist?	Informal contextual and societal factors	Confounding factors	

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This oversight leads to problems in contextually adapted versions of the instrument as these adaptations often fail to evaluate the validity of the original conceptual models—or in some cases, are hindered by the absence of a clearly defined original conceptual model. Moreover, the overall concepts captured by existing instruments are heterogeneous, as indicated in Table 2. 'Financial toxicity' was the most commonly addressed concept, found in three instruments, COST, PROFFIT, and FIT. However, the extent of item coverage based on our allocation process varied among them. Specifically, while COST primarily focused on the 'psychological financial response,' FIT and PROFFIT also included themes such as 'financial coping behavior' and 'financial coping ability' as outlined in the conceptual framework by Schlander et al. [1] (refer to Table 2).

Our analysis further showed that the instruments mainly address constructs related to the psychological experience of SEI, or how individuals cope with SEI. However, they currently lack measures for other important constructs, such as direct costs [1]. Given that the topic of SEI of cancer is relatively new, we recommend that future PRO instrument development or validation studies should clarify their theoretical frameworks to comprehensively cover all aspects of the SEI of cancer.

4.1 Limitations

This study has several limitations. First, our search was performed for English only literature across three databases: PubMed, Web of Science, and Google Scholar. While these databases are widely used and comprehensive, it is important to acknowledge that there are other databases recommended by the Cochrane Handbook [38] that may contain additional relevant records. However, we selected our three databases based on two main reasons. First, our search process followed a pearl-growing approach, aiming to capture all articles cited in our primary sources beyond the typical medical and science fields. In this regard, Google Scholar proved to be a valuable addition alongside the well-established PubMed and Web of Science. Second, Google Scholar yielded the highest number of records and covered most of the records retrieved from the other two databases. Therefore, we considered that an additional search in other databases is not necessary for the scope of this study. In addition, we only consider English literature in this study, which may not include instruments in other languages. Therefore, it is important to acknowledge that while our selection process was thorough, there may still be relevant literature that was not captured by the search strategy.

A second limitation of our study is that we focused specifically on instruments designed to measure the SEI of cancer. Consequently, the instruments that measured the SEI of cancer only as a sub-domain were not included in our analysis. This approach may have excluded valuable tools that offer insights into the broader context of SEI within cancer research.

Finally, our standardized assessment and item allocation process was based on the judgement of the authors, which is inherently subjective and might differ from other appraisers. Nevertheless, our team is comprised of experts with extensive knowledge in instrument development and validation. This collective expertise mitigates potential biases during the assessment process.

5 Conclusion

This systematic review evaluated the psychometric properties of 21 PRO instruments (9 original and 12 contextually adapted versions) using the EMPRO tool. Our findings show variations in both overall and attribute-specific EMPRO scores across the instruments assessed. Many attributes could not be adequately scored due to insufficient available information.

Remarkably, the original version of the COST instrument was the sole instrument with a score above 50, indicating adequacy according to the EMPRO tool's criteria. However, evidence supporting the contextual adaptations of the COST instrument was limited. Additionally, our findings suggest that the PROFFIT instrument [9] exhibits potential adequacy not only within the Italian context but also countries with similar healthcare systems, contingent upon further validation studies.

We also found that none of the instruments covered all the themes of the SEI conceptual framework [1]. The most addressed themes in the included instruments are 'financial coping ability,' 'psychological financial response,' and 'financial coping behavior.'

In general, we recommend future studies address contextual differences when developing or validating PRO instruments for assessing the SEI of cancer. Such studies need to comprehensively address the relevant themes of SEI by considering the established conceptual framework for their content validity. These are essential for enhancing the robustness and applicability of these instruments across diverse settings and populations.

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Declarations

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