The Socioeconomic Impact of Cancer and Cancer Care on Patients and Their Relatives: Assessing the Content Validity of Dedicated Patient-Reported Outcomes Measurement (PROM) Instruments

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BACKGROUND

- The socioeconomic impact (SEI) of cancer on patients and their families is increasingly recognized as an important area of research.
- A number of instruments have been developed to measure SEI from the perspective of patients and their relatives.
- A standardized comparison of these instruments' quality and content validity is lacking, and existing evaluations often differ in their methods and criteria—highlighting the need for greater consistency in SEI measurement.

METHODS

- **Figure 1** illustrates the PRISMA flowchart for the pearl identification and growing approach.
  - We utilized an existing database to identify instruments along with their key validation, development, and application studies.
  - We applied a multi-step pearl growing search strategy.
- Next, we conducted a standardized assessment using the Evaluating the Measurement of Patient-Reported Outcomes (EMPRO) tool to assess quality.
- Finally, we applied the conceptual framework proposed by the OECI Task Force to map instrument items and assess their content validity.

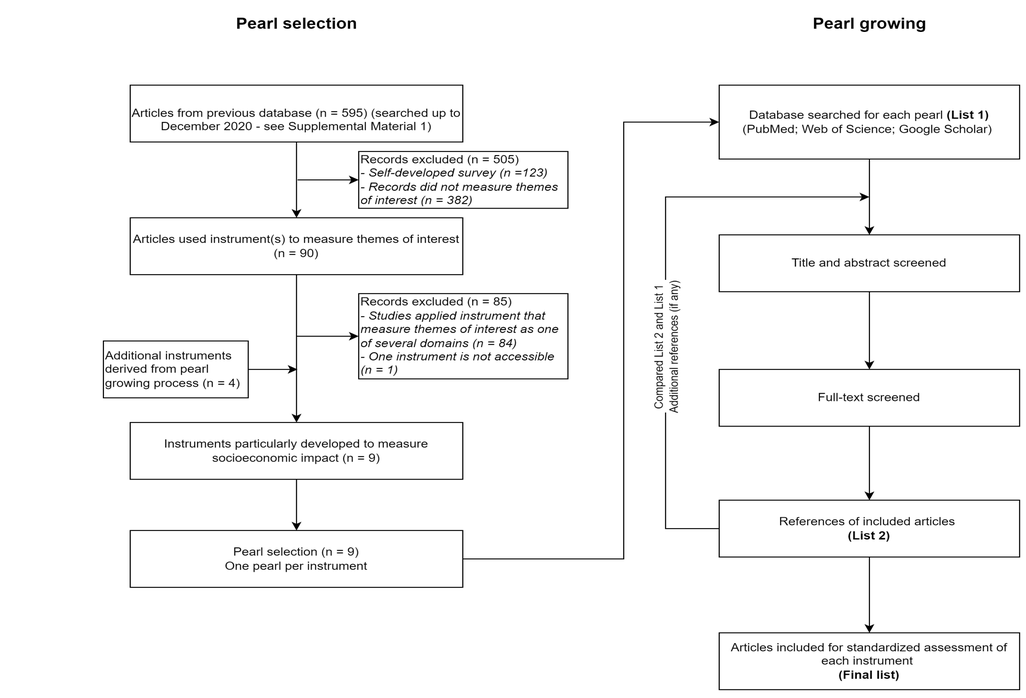

Figure 1. PRISMA chart – pearl selection and overall pearl-growing search process.

DISCUSSION & CONCLUSIONS

- Using the EMPRO tool, we found significant variation in the quality and use of current SEI instruments.
- Our content validity analysis revealed that none of the existing SEI instruments comprehensively cover all domains of the OECI framework, leaving important aspects of SEI unaddressed.
- This study illuminates the need for future research and instrument validation aligned with a clear conceptual framework to comprehensively measure the SEI of cancer.
- The OECI framework offers a comprehensive, policy-relevant foundation for the development and evaluation of SEI instruments focused on the impact of cancer on patients and their families.

KEY REFERENCES

Schlander M, van Harten W, Retèl VP, Pham PD, Vancoppenolle JM, Ubels J, et al. The socioeconomic impact of cancer on patients and their relatives: Organisation of European Cancer Institutes task force consensus recommendations on conceptual framework, taxonomy, and research directions. Lancet Oncol. 2024;25(4):e152–63.

Pham PD, Schlander M, Eckford R, Hernandez-Villafuerte K, Ubels J. Developing a conceptual framework for socioeconomic impact research in European cancer patients: a "best-fit" framework synthesis. Patient. 2023;16(5):515–36.

OBJECTIVES

This study aimed

- to assess the content validity of existing SEI instruments and determine whether any are suitable PRO measures for evaluating the SEI of cancer, using the Organization of European Cancer Institutes (OECI) Task Force conceptual framework as a reference;
- to provide quantitative evidence and identify what additional information is needed for future validation and/or application of PRO instruments measuring the SEI of cancer.

RESULTS

Pearl Identification and Growing

- Nine pearls from nine instruments were identified.
- Of 561 articles citing these pearls across three databases, 69 were included for standardized assessment.
- The COST instrument was the most frequently applied (n = 57), followed by IFDFW (n = 15) and EHQ (n = 6). Several newly developed instruments—such as FIT, SFDQ, HARDS—had not yet been applied at the time of this study.

Standardized Assessment

- 21 validation studies were investigated in the standardized assessment.
- The overall and attribute-specific EMPRO scores varied significantly across the instruments **(Figure 2)**.
- Only one instrument (COST) met the adequate EMPRO overall score of 50.

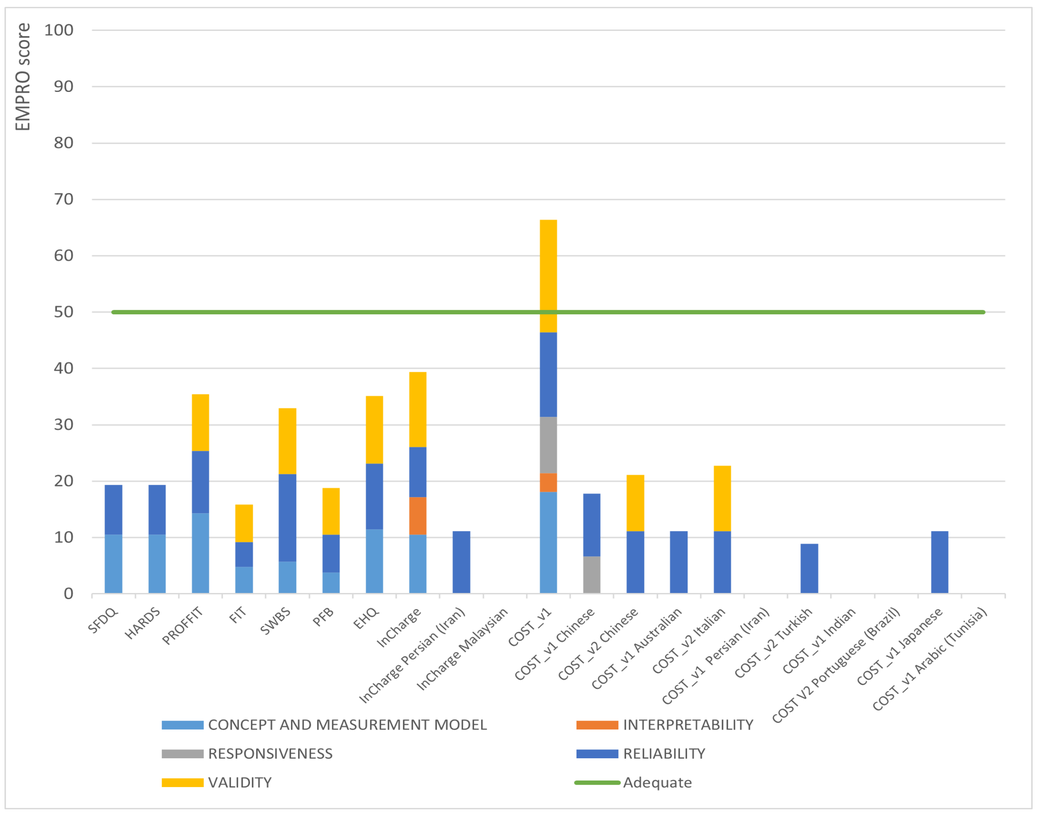

Figure 2. The overall EMPRO and attributable scores of included instruments. Instruments with no score: Unable to score due to unavailable/limited information.

Concepts Reflected by the Instruments

Instrument name	Relevant theme(s) covered	Other themes not covered
Comprehensive Score for financial Toxicity (COST)	*Financial coping ability; Psychological financial response; Indirect costs*	*Direct costs; Financial coping behavior; Confounding factors*
InCharge - Financial Wellbeing Scale	*Psychological financial response; Financial coping ability; Financial coping behavior*	*Direct costs; Indirect costs; Confounding factors*
Financial Index of Toxicity (FIT)	*Psychological financial response; Financial coping ability; Financial coping behavior; Indirect costs*	*Direct costs; Confounding factors*
Socioeconomic well-being scale (SWBS)	*Financial coping ability; Confounding factors; Psychological financial response*	*Direct costs; Indirect costs; Financial coping behavior*
Economic Hardship Questionnaire (EHQ)	*Financial coping behavior; Psychological financial response; Financial coping ability*	*Direct costs; Indirect costs; Confounding factors*
The Hardship And Recovery with Distress Survey (HARDS)	*Psychological financial response; Financial coping ability, Financial coping behavior*	*Direct costs; Indirect costs; Confounding factors*
Personal Financial Burden (PFB)	*Financial coping behavior; Financial coping ability*	*Direct costs; Indirect costs; Psychological financial response; Confounding factors*
Patient-Reported Outcome for Fighting FInancial Toxicity (PROFFIT)	*Financial coping ability; Psychological financial response; Financial coping behavior; Confounding factors; Direct costs*	*Indirect costs*
Subjective Financial Distress Questionnaire (SFDQ)	*Psychological financial response; Financial coping ability; Psychological financial response; Indirect costs; Confounding factors*	*Direct costs*

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