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Systematic review of financial burden assessment in cancer: Evaluation of measures and utility among AYAs and caregivers

John M. Salsman, PhD[1], **Suzanne C. Danhauer, PhD**[1], **Justin B. Moore, PhD**[1], **Edward H. Ip, PhD**[1], **Laurie E. McLouth, PhD**[2], **Chandylen L. Nightingale, PhD**[1], **Christabel K. Cheung, PhD**[3], **Kristin Bingen, PhD**[4], **Reginald D. Tucker-Seeley, ScD**[5], **Denisha Little-Greene, PA, MMS**[1], **Dianna S. Howard, MD**[1], **Bryce B. Reeve, PhD**[6]

[1]Wake Forest School of Medicine, Winston Salem, NC

[2]University of Kentucky College of Medicine, Lexington, KY

[3]University of Maryland, Baltimore, MD

[4]Medical College of Wisconsin, Milwaukee, WI

[5]University of Southern California, Los Angeles, CA

[6]Duke University School of Medicine, Durham, NC

Abstract

Background: The cost of cancer care is rising and represents a stressor that has significant and lasting effects on quality of life for many patients and caregivers. Adolescents and young adults (AYAs) with cancer are particularly vulnerable. Financial burden measures exist but have varying evidence for their validity and reliability. The goal of this systematic review is to summarize and evaluate measures of financial burden in cancer and describe their potential utility among AYAs and their caregivers.

Methods: We searched PubMed, Embase, Cochrane Library, CINAHL and PsychINFO for concepts involving financial burden, cancer, and self-reported questionnaires, limiting the results to the English language. We discarded meeting abstracts, editorials, letters, and case reports. We used standard screening and evaluation procedures for selecting and coding studies, including consensus-based standards for documenting measurement properties and study quality.

Results: We screened 7,250 abstracts and 720 full-text articles to identify relevant articles on financial burden. Of those, 86 met our inclusion criteria. Data extraction revealed 64 unique measures that assess financial burden across material, psychosocial, and behavioral domains. One

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Corresponding Author: John M. Salsman, PhD, Wake Forest School of Medicine, Medical Center Boulevard, Winston Salem, NC 27157; jsalsman@wakehealth.edu, 336-713-3613.

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Conceptualization, design: Salsman, Moore, Danhauer, Reeve
Methodology: Salsman, Danhauer, Moore, Ip, Reeve
Analysis: Ip, Reeve, Salsman
Data interpretation and results: Danhauer, Moore, Ip, Reeve, Salsman
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measure was developed specifically for AYAs and none for their caregivers. The psychometric evidence and study qualities revealed mixed evidence of methodological rigor.

Conclusion: Several measures assess the financial burden of cancer. They were primarily designed and evaluated in adult patient populations with little focus on AYAs or caregivers, despite their increased risk of financial burden. These findings highlight opportunities to adapt and test existing measures of financial burden for AYAs and their caregivers.

Precis:

Many self-report measures of financial burden in cancer exist, but very few have adequate data to support robust psychometric properties or capture material, psychosocial, and behavioral domains. A particularly salient need is to adapt and test existing measures of financial burden for AYAs and their caregivers.

Keywords

cancer; measurement; finances; systematic review; young adult; caregivers

Background

The cost of cancer care is rising and represents a significant stressor with lasting effects on quality of life for patients and their caregivers.[1–3] Survivors of cancer are more likely to report higher out-of-pocket medical costs, work-related productivity loss, depletion of assets, and medical debt including bankruptcy than those without a cancer history.[4–6] Moreover, the adverse financial impact of cancer is often shared by family caregivers (e.g., parents, partners, siblings), with 25% of caregivers reporting high levels of financial strain from decreasing financial assets, increasing out-of-pocket costs, and productivity loss in their jobs.[7–9]

Adolescents and young adults (AYAs) with cancer, defined as those diagnosed with cancer from the ages of 15 to 39 years old,[10] are particularly vulnerable to the financial burden of cancer care. Worldwide, there are more than 1,000,000 new diagnoses of cancer annually in AYAs.[11] Inadequate insurance coverage and limited financial assets place AYAs at greater risk of financial burden compared to any other age group with cancer.[12–14] The AYA population is increasingly racially and ethnically diverse. Although not well-characterized in AYA research, racial and/or ethnic disparities in financial burden are well-documented in cancer research,[15, 16] suggesting that racial/ethnic AYA minority groups may have additional risk for financial burden compared to white AYA cancer survivors.

Multiple terms have been used to describe the adverse financial impact of cancer such as financial hardship, financial burden, financial toxicity, and financial distress.[5, 13, 17–29] We define financial burden as the adverse impact of cancer and treatment-related costs on patients and/or their families. Consistent with current multidimensional perspectives offered in cancer survivorship research, financial burden may include material (e.g., reduction in income, medical debt), psychosocial (i.e., distress about medical costs), and behavioral domains (i.e., strategies such as forgoing medical care).[30–32]

Multiple measures have been developed to assess financial burden with the vast majority focusing on the material dimension and relatively less attention paid to psychosocial or behavioral dimensions.[30] To advance screening and treatment of this critical problem, a synthesis and evaluation of existing measures of financial burden is needed. Therefore, our goal is to build upon existing systematic reviews[30, 33] *and to extend those reviews in important new directions* by summarizing and evaluating the psychometric properties of financial burden measures in cancer for <u>all patients and caregivers</u> while describing their potential utility among AYAs and their caregivers specifically. We sought to address three key questions: (1) How is self-reported financial burden assessed from the cancer patient or caregiver perspective?; (2) What are the psychometric properties of the available financial burden measures?; and (3) Which measures show potential utility for AYAs with cancer and caregivers in particular?

Methods

Search Strategy

A reference librarian designed the literature search to identify published studies. We searched PubMed, Embase, Cochrane Library, CINAHL Complete (Ebsco) and PsycINFO (Ebsco), through March 20, 2019, using a combination of relevant subject headings, concepts, and text words involving financial burden, cancer, and self-reported questionnaires. Detailed strategies are available in Supplemental Table 1.

Eligibility Criteria

Eligibility criteria included (a) peer-reviewed journal articles; (b) empirical studies; (c) English language publications and measure; (d) defined cancer sample or subsample (any age, type, or phase of treatment) or their caregivers/proxies; (e) inclusion of self- or proxy-report measure(s) of the personal or family *subjective* financial impact for patients or their caregivers/proxies; (f) report scores for subscales/subdomains individually or in aggregate form; and (g) report psychometric evidence for the measure (i.e., some evidence of reliability <u>or</u> validity). Case studies, commentaries, conference abstracts, reviews, dissertations, or qualitative research unrelated to measurement development were excluded. We also excluded studies that solely focused on out-of-pocket costs. While these costs are important *objective* indicators of financial burden, they capture only one aspect of the material dimension and do not fully reflect the broader financial burden experienced by patients and their caregivers.

Study Selection

Covidence (v1906), a Cochrane technology platform, was used to manage study reviews and coding. Abstracts were initially screened in sets of 20 by all reviewers to determine whether they met inclusion criteria for full text review. Conflicts were discussed as a group, and we screened another set of 20 abstracts until there was good agreement among reviewers (≥80%). Subsequently, individual rater pairs screened the remaining abstracts. Full-text articles were retrieved for all potentially eligible abstracts and independently screened by rater pairs. The lead author, in consultation with the larger study team, resolved any discrepancies to determine the final set of studies included in the review.

Data Coding

Rater pairs then independently extracted data elements from all eligible full-text articles. Any discrepancies in extracted data were resolved through discussion among raters until consensus was reached. Demographic (sample size, age, % women, % racial or ethnic minorities), clinical (cancer type, stage, phase of cancer care), study characteristics (country, research design), and measure characteristics were extracted. Measure characteristics including instrument name, type (patient- or caregiver-reported), financial burden domain assessed (e.g., material, psychosocial, or behavioral), number of questions, number and type of responses, and recall period. In addition, two PhD trained psychometricians extracted data on the evidence for the reliability and validity of all measures.

Psychometric Properties & Study Quality Assessment

A subset of the identified measures of financial burden were selected for a more detailed review. The selected measures had to be multi-item scales from psychometric studies with some evidence for both their reliability and validity in patients with cancer. The psychometricians independently evaluated each instrument based on modified COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) criteria[34] (Supplemental Table 2). Key COSMIN modifications included the additions of category of score interpretability and of rating level of “very good” above “adequate/sufficient”. Criteria included evidence for the instrument’s structural validity, internal consistency reliability, test-retest reliability, content validity, criterion validity, construct validity, cross-cultural validity/measurement invariance, responsiveness, and interpretability of scores. When multiple studies included the same measure, criteria ratings were based on the cumulative evidence across all relevant studies. Each criterion was graded as very good, adequate, inadequate, or not reported. Discrepancies were resolved by consensus. Lastly, the psychometricians reviewed each of these studies individually to evaluate the overall quality of the study, using a modified version of the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies.[35] Criteria were selected based on their relevance to studies of psychometric properties and so we excluded items that only applied to cohort studies with an epidemiological focus (e.g., assessment of exposure over time). We included the study’s clarity of objective, defined population, appropriateness of participation rate, justified sample size for study objective, appropriate assessment points, well defined variables, and limited loss to follow-up. Criteria were rated as yes, no, or not reported.

Results

Study Selection

The search of the electronic databases retrieved 9,113 citations (Figure 1). After removal of duplicates, 7,250 remained and were evaluated based on title and abstract. Of these, 6,530 did not meet the inclusion criteria. 720 potentially relevant references were screened with a full text review. Of these, 86 studies met inclusion criteria and yielded summary data for reliability and/or validity of financial burden measures. Fourteen studies (comprising 10 measures) had sufficient information for further, in-depth psychometric evaluation.

Overall Description of Studies and Measure Characteristics

Eighty-six studies were included in our review, accounting for over 55,000 patients and nearly 4,000 caregivers (e.g., parent, spouse/partner, or other family member). Seventy-nine percent (68/86) were published in the last decade with 74% (50/68) of those within the last five years. The majority of studies focused on U.S. samples (80%; 69/86) and included mixed cancer types (73%; 63/86). The samples were primarily female (72% of studies included >50% female participants; 62/86). Only 15% of studies had ≥30% racial/ethnic minority representation (13/86), and only 9% of studies included a majority of AYAs in their sample (8/86; with four of those eight studies focusing on adult survivors of pediatric cancers). The vast majority of studies used a quantitative approach (97%; 83/86). Cross-sectional designs (73%; 63/86) were more than three times as common as longitudinal ones (23%; 20/86). Only a few studies used either a mixed-methods approach (2%; 2/86)[36, 37] or a qualitative approach (1%; 1/86).[38] Supplemental Table 3 provides study characteristics by individual project.

Overall, we identified 64 unique measures used to assess financial burden in cancer survivorship. Of these, 49 were multi-item measures and 15 were single item measures of financial burden. All measures reviewed were designed for adult self-report with 81% (52/64) patient-reported measures of financial burden and 23% (15/64) caregiver-reported measures (three measures had both caregiver and patient versions and none were proxy-reported measures). One measure was developed specifically for AYAs but focused on survivors of childhood cancer[39], and no measures were designed for caregivers of AYAs. The material domain of financial burden was captured by 70% of measures (45/64), followed closely by the psychosocial (61%; 39/64) and behavioral (44%; 28/56) domains. Only twelve measures captured content from all three domains (19%; 12/64). Supplemental Table 4 provides additional details about specific financial burden items/measures for individual studies.

Psychometric Analysis and Study Quality

Ten measures (8 patient-reported; 2 caregiver-reported) from 14 studies were identified for in-depth evaluation of their psychometric properties. Across the 9 COSMIN criteria used to evaluate the psychometric qualities of the individual measures, combined ratings of “adequate” or “very good” ranged from 44% to 78% (Table 1). The Comprehensive Score for Financial Toxicity (COST),[25, 26] Patient Roles and Responsibilities Scale,[40] and Singapore Caregiver Quality of Life Scale: Financial Well-being Subscale[41] all received ratings of “adequate” or “very good” across >60% of the categories. None of the patient-reported measures provided sufficient information to merit “adequate” or “very good” ratings for criterion validity, cross-cultural validity/measurement invariance, or responsiveness. Only the caregiver-reported measure, the Singapore Caregiver Quality of Life Scale: Financial Well-being Subscale, had sufficient data to receive an “adequate”/”very good” rating for cross-cultural validity/measurement invariance. Notably, the Impact of Cancer for Childhood Cancer Survivors: financial problems subscale[39] was the only measure specific to AYAs, receiving ratings of “adequate” or “very good” across a majority (56%) of the COSMIN criteria. Only two measures, the Patient Roles and Responsibilities Scale[40] and the Caregiver Roles and Responsibilities Scale[42] included item content across all three domains of financial burden: material, psychosocial, and behavioral. The study quality was uniformly strong for each of these 14 studies (Table 2).

Discussion

Interest in the patient and caregiver experience of financial hardship has burgeoned in the last decade as evidenced by a doubling of the number of publications during that time. Capturing and accurately representing patient and caregiver experiences of financial burden is critical to advance research and clinical practice and to develop interventions that address the financial burden of cancer survivors and their caregivers. The current systematic review addresses an important gap in the literature by including an assessment of measures specifically for use among AYAs. Overall, we found that although many self-report measures of financial burden exist, very few have adequate data to support robust psychometrics, most do not assess all three domains of financial burden, and almost none focus on AYAs or their caregivers. Measure characteristics, including their psychometric strengths and limitations, their evidence for use among AYAs, and implications for research are discussed below.

Patient reports of financial burden accounted for 52 unique measures in our systematic review; caregiver-reports accounted for 15. Collectively, these self-report approaches included multi-item scales that yield *overall* financial burden scores,[25, 43] multi-item scales that yield financial burden *subscale* scores,[39, 44, 45] and single-item approaches developed de novo for individual research studies[5, 46–48] or drawn from existing, population-based research studies.[19, 20, 22, 49] While brief assessments are desired for reduced respondent burden, they may not capture the breadth and depth of the financial burden experience of cancer survivors and caregivers.

Conceptual models of financial burden in cancer emphasize the material, psychosocial, and behavioral domains.[31] Whereas the material domain can be partially indicated by objective cost data (e.g., out-of-pocket expenditures), self-report data remain critical to describe other aspects of the material burden (e.g., reduction in household income) experienced by cancer survivors and their caregivers. Self-report data are especially relevant for the psychosocial and behavioral domains that capture how cancer survivors and their caregivers feel about financial burden (e.g., distress from the reduction in financial resources) and the purposeful effort they engage in to “make ends meet” (e.g., financial adjustments to balance household budgets) as they manage and navigate cancer survivorship. Of the measures included in our review, 19% had item content that reflected all three domains. As expected, the material dimension was the most frequently assessed domain of financial burden in this review, captured by 70% of measures. However, the psychosocial and behavioral domains were relatively well-represented, captured by 61% and 44%, respectively. The encouraging representation of psychosocial and behavioral domains may reflect the use of newer measures of financial burden (e.g., COST) and appreciation for a need to progress from an over-reliance on material aspects of financial burden to inform a more complete understanding of patient and caregiver experiences.

Only ten measures (eight patient-report and two caregiver-report) provided adequate psychometric detail to inform a rigorous evaluation of their quality among patients and caregivers with cancer. Further, only two of those measures captured all three domains of financial burden. Of the ten measures we evaluated, the majority demonstrated “adequate” to “very good” ratings across multiple psychometric criteria. In general, these measures demonstrated relative strengths in their structural validity, internal consistency reliability, test-retest reliability, construct validity, interpretability, and content validity. However, additional testing and evaluation is needed to demonstrate greater utility of these measures. First, responsiveness, criterion validity, and cross-cultural validity/measurement invariance were largely absent. The Financial Well-being subscale of the Singapore Caregiver Quality of Life Scale[41] was the only measure that provided sufficiently strong support for this psychometric category. Very few of the measures were tested among sizeable subgroups of racial or ethnic minority participants, rural patients, or even AYAs who may be more likely to be uninsured or underinsured and thus at greater risk of financial burden.[12–14, 50–55] Second, too few studies leveraged longitudinal designs to inform assessments of responsiveness and criterion validity. Since financial burden may fluctuate over time and across the cancer care continuum,[56] longitudinal designs are needed to address the lack of responsiveness data. Longitudinal approaches can also strengthen the evidence base for criterion validity.

Lastly, only one scale was designed to assess the financial burden among AYAs. The Financial Problems subscale of the Impact of Cancer Scale is a brief assessment of the adverse impact of financial burden among post-treatment survivors.[39] However, it was validated with adult survivors of childhood cancer. Other promising measures, the COST and the Patient Roles and Responsibilities Scale have had limited testing with AYA subgroups.[25, 40] The lack of validated measures of financial burden among AYAs represents an important opportunity to adapt and test existing measures or to develop new measures to address this critical gap. This is important, as changing healthcare coverage among AYAs in their mid-20s as they age out of eligibility for extended coverage under their parents’ insurance through the Affordable Care Act presents additional challenges.[29] Similarly, older AYAs may be at particular risk as many have mortgages and dependents with fewer financial reserves.[57] Altogether, these unique factors underscore the importance of capturing the lived experiences, developmental milestones, and perspectives of AYA patients and their caregivers managing the financial burden of cancer.

No caregiver studies were specifically focused on AYAs, though a small number of studies focused on caregivers of pediatric patients with cancer.[24, 55, 58–60] These were rarely older adolescents (ages 15-17) or emerging adults (ages 18-25). Assessing the financial experience of these AYA and caregiver subgroups is critical, as they face unique financial needs and challenges. The subjective experience of financial burden among older adolescents may not warrant assessment as their caregivers often maintain primary financial responsibility. In contrast, emerging adults are navigating financial autonomy and independence from their parent caregiver(s), perhaps heightening distress about the financial impact of cancer. As emerging adults may be living at home or pursuing educational goals and not financially established, their parent caregivers may assume additional and more persistent financial responsibility, compromising their own financial well-being. For emerging adults whose caregivers are a partner, significant other, or sibling, financial burden may be experienced differently by both the cancer patient and the caregiver. Assessing the caregiver perspective alone is likely sufficient for older adolescents but assessing the patient and caregiver perspective in tandem would be ideal for evaluating financial burden among emerging adults. These nuances need to be considered in research designs as well as measurement development for AYAs and their caregivers.

This study has limitations. We restricted our search to English language measures and measures tested among patients with cancer or their caregivers. Although measures developed and tested in non-English languages or among other health conditions may further inform assessment of financial burden, the cost of cancer care in the United States is rapidly rising and embedded within existing federal health policy environments.[61] A majority of participants were adult women who were not AYAs and there was little racial or ethnic minority representation. Thus, the particular experiences of financial burden, including behavioral strategies for managing the costs of cancer, may not generalize to groups that are more diverse. Another limitation is we did not include measures that assessed out-of-pocket costs for patients and families. While this is a critically important aspect of financial burden in cancer, out-of-pocket costs only inform one aspect of the material subdomain. We prioritized the self-reported subjective perspective and ensured sufficient breadth by exploring material as well as psychosocial and behavioral domains of financial burden in cancer.[31]

Despite these limitations, this study had a number of strengths that increase the impact of this work. This is the first systematic review and psychometric evaluation of measures of financial burden for patients with cancer and their caregivers. Our review was pre-registered in PROSPERO and adhered to the “Preferred Reporting Items for Systematic Reviews and Meta-Analyses” guidelines.[62] Our comprehensive search of five databases included multiple reviewer pairs, counter-balanced to minimize rater bias. All reviewers had advanced doctoral degrees and represented a diversity of training backgrounds (measurement science, clinical psychology, pediatric psychology, social welfare, health education, and public health). Data extracted from all studies focused on demographic, clinical, and measure characteristics, including reliability and validity. For measures that provided more detailed psychometric data, we conducted in-depth evaluations of the psychometric rigor and study quality using consensus standards. We identified a number of strengths and specific recommendations for next steps.

Summary and future directions

In closing, this timely project highlights the need for more research on the measurement of financial burden among AYA cancer survivors and their caregivers. We have provided a thorough and detailed description of the available measures used to assess financial burden for cancer survivors and caregivers. Some of these measures have sufficiently strong psychometric properties to merit further use and evaluation. Unfortunately, relatively little attention has been focused on financial burden among at-risk patient populations, including AYAs and their caregivers. This gap in the literature represents a crucial opportunity to adapt and test existing measures of financial burden for AYAs and their caregivers. Serial assessment could be used to better understand the impact of financial burden over time, identify who might be most at risk, and determine when they are most in need of support. Accurate assessment is a key step in ensuring that patients and families have a voice in their experience and can inform and contribute to the development, implementation, and evaluation of supportive care interventions to inform patient advocacy, better address their needs, influence health policy, and ultimately reduce the adverse impact of financial burden.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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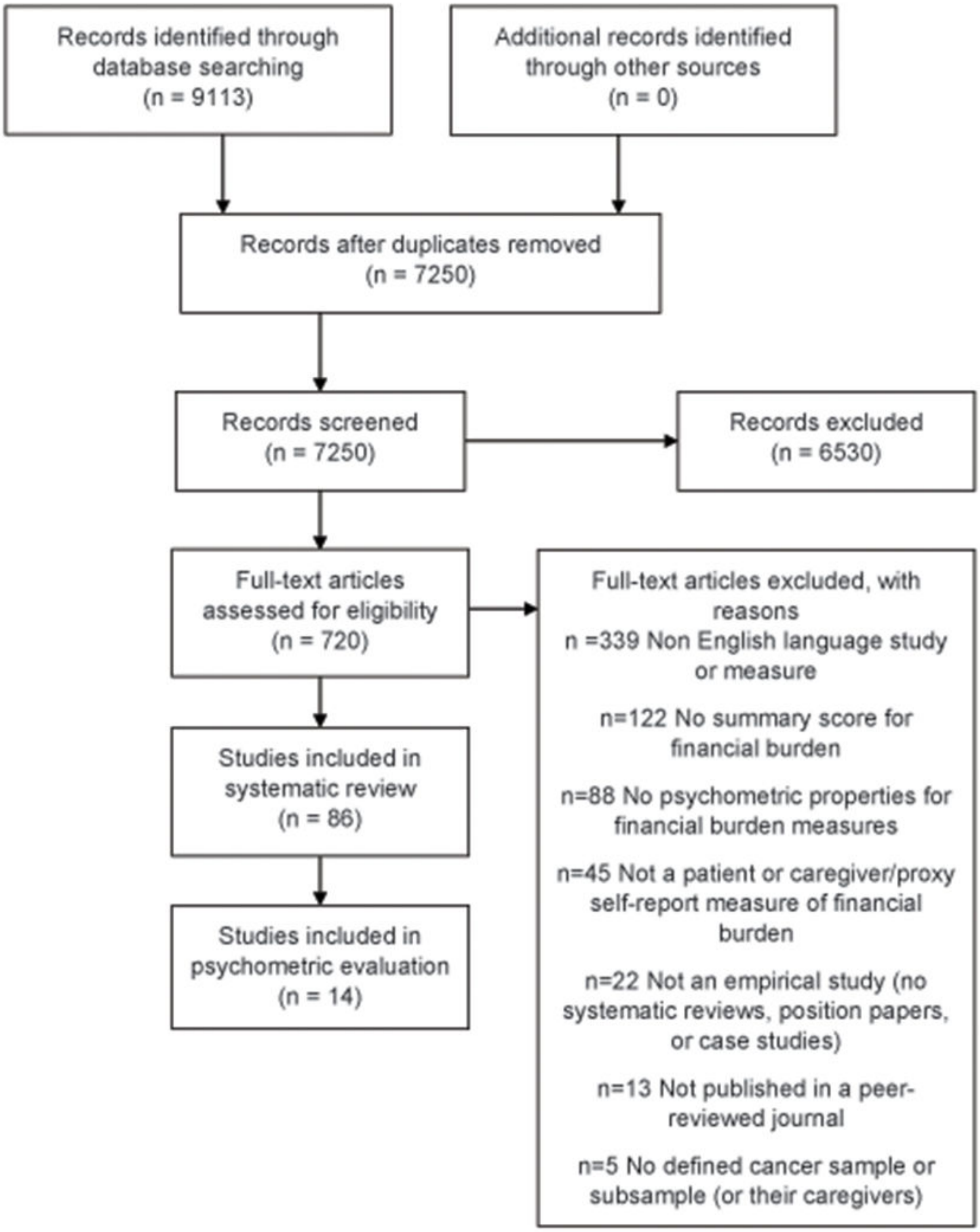

Figure 1.

PRISMA Flow Diagram

Table 1.

Psychometric Properties of Financial Burden Measures

Measure Name	Structural Validity	Internal Consistency	Reliability	Construct Validity	Cross-Cultural Validity/ Measurement Invariance	Criterion Validity	Responsiveness	Interpretability	Content Validity
Patient-Reported									
Cancer Problem-in-Living Scale[38, 63]	very good	adequate	not reported	adequate	not reported	not reported	not reported	adequate	adequate
Chronic Cancer Experiences Questionnaire[37]	adequate	adequate	not reported	adequate	not reported	not reported	not reported	adequate	very good
Comprehensive Score for Financial Toxicity[25, 26]	very good	very good	adequate	very good	inadequate	not reported	not reported	adequate	very good
Impact of Cancer for Childhood Cancer Survivors: Financial Problems subscale[39]	very good	adequate	inadequate	very good	not reported	not reported	not reported	very good	very good
Patient Roles and Responsibilities Scale: Financial Well-being subscale[40]	very good	adequate	adequate	adequate	not reported	not reported	inadequate	adequate	very good
Quality of Life in Adult Cancer Survivors: Financial Problems subscale[36, 54, 64]	very good	adequate	not reported	very good	not reported	not reported	not reported	adequate	very good
Socioeconomic Well-Being Scale: Material Capital subscale[65]	very good	very good	not reported	very good	not reported	not reported	not reported	adequate	very good
Not reported (study-specific measure of financial burden/ worry)[66]	very good	adequate	not reported	adequate	not reported	not reported	not reported	very good	not reported
Caregiver-Reported									
Singapore Caregiver Quality of Life Scale: Financial Well-being subscale[41]	very good	very good	adequate	very good	very good	not reported	not reported	adequate	very good
Caregiver Roles & Responsibilities Scale: Financial Well-being subscale[42]	very good	adequate	adequate	not reported	not reported	not reported	not reported	adequate	very good

Table 2.

Study Quality Assessment

Measure Name	Study	Objective	Study Population	Participation Rate	Sample Size Justification	Sufficient Timeframe	Variables Defined	Loss to Follow-Up
Patient-Reported								
Cancer Problem-in-Living Scale: Employment/Financial Problems subscale	Baker 1999[38]	Yes	Yes	NR	NA	Yes	NA	Yes
	Zhao 2009[63]	Yes	Yes	Yes	NR	NA	Yes	NA
Chronic Cancer Experiences Questionnaire: Financial Advice subscale	Harley 2019[37]	Yes	Yes	Yes	NR	NA	Yes	NA
Comprehensive Score for Financial Toxicity	de Souza 2014[26]	Yes	Yes	NR	Yes	Yes	Yes	NA
	de Souza 2017b[25]	Yes	Yes	NR	Yes	Yes	Yes	NA
Impact of Cancer for Childhood Cancer Survivors: Financial Problems subscale	Zebrack 2010[39]	Yes	Yes	Yes	No	Yes	Yes	NA
Patient Roles and Responsibilities Scale: Financial Well-being subscale	Shilling 2018[40]	Yes	Yes	Yes	NR	NR	Yes	Yes
Quality of Life in Adult Cancer Survivors: Financial Problems subscale	Avis 2005[36]	Yes	Yes	Yes	Yes	Yes	Yes	NA
	Carver 2006[64]	Yes	Yes	Yes	No	Yes	Yes	NA
	Morrow 2014[54]	Yes	Yes	No	No	Yes	Yes	NA
Socioeconomic Well-Being Scale: Material Capital subscale	Head 2008[65]	Yes	Yes	No	Yes	Yes	Yes	NA
Not reported (study-specific measure of financial burden/worry)	Veenstra 2014[66]	Yes	Yes	Yes	No	Yes	Yes	NA
Caregiver-Reported								
Singapore Caregiver Quality of Life Scale: Financial Well-being Subscale	Cheung 2019[41]	Yes	Yes	NR	Yes	Yes	Yes	No
Caregiver Roles & Responsibilities Scale: Financial Well-being subscale	Shilling 2019[42]	Yes	Yes	Yes	NR	Yes	Yes	Yes

Note: NA= not applicable, NR=not reported