

REVIEW

Methods for measuring financial toxicity after cancer diagnosis and treatment: a systematic review and its implications

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Patients experiencing financial distress as a side-effect of cancer are not only reported in the United States, but also in third-party payer healthcare systems in Europe. Since validated survey instruments are a prerequisite for robust and comparable results, we aimed to compile and classify available instruments to enable both a better understanding of the underlying construct of financial toxicity and to facilitate further studies that are adjustable to various healthcare systems. We did a systematic literature search on studies that provide data on perceived cancer-related financial distress experienced by adult patients using PubMed, CINAHL and Web of Science databases up to 2018. We analyzed all detected instruments, items domains and questions with regard to their wording, scales and the domains of financial distress covered. Among 3298 records screened, 41 publications based on 40 studies matched our inclusion criteria. Based on the analysis of 352 different questions we identified 6 relevant subdomains that represent perceptions of and reactions to experienced financial distress: (i) active financial spending, (ii) use of passive financial resources, (iii) psychosocial responses, (iv) support seeking, (v) coping with care or (vi) coping with ones' lifestyle. We found an inconsistent coverage and use of these domains that makes it difficult to compare and quantify the prevalence of financial distress. Moreover, some existing instruments do not reflect relevant domains for patients in third-party payer systems. There is neither a consistent understanding of the construct of financial burden nor do available instruments cover all relevant aspects of a patients' distress perception. We encourage using the identified six domains to further develop survey instruments and adjust them to different health systems.

Key words: oncology, cancer, cost, financial toxicity, financial distress, poverty risk

Introduction

While scientific advances in oncology bring more treatment options to an expanded number of cancer patients, payers are noticing the impact of rising treatment costs [1, 2] and longer treatment duration on drug budgets [3]. Apart from this economic impact of cancer treatment on healthcare systems, economic side-effects also become discernible at the patient level. So far, research on the individual financial effects of cancer therapy has largely focused on quantifying objective financial burden such as out-of-pocket (OOP) expenses [4]. In contrast, the subjective financial impact understood as the consequence of cost concerns on the individual patient has gained interest only in recent years.

Studies show that anxiety and stress as possible individual side-effects of cancer therapy costs are associated with a number of adverse health outcomes, both physical and mental [5, 6]. Patients experiencing considerable subjective financial distress may alter their care to defray OOP expenses [7], may have inferior health-related quality of life (HRQOL) [8] or even lower chances of survival [9]. Cancer-related financial distress was reported even by insured patients in the United States [7]. As a result, the term 'financial toxicity' has been established as a generic term, covering both 'objective financial burden' and 'subjective financial distress' experienced by cancer patients [10].

First systematic reviews focus on the prevalence of financial toxicity in different health care contexts [3, 4, 11–14]. However,

the inconsistent use of definitions, terms, and measures of financial toxicity makes it difficult to summarize the available evidence [13]. To obtain comparable results, the use of standardized instruments based on the same constructs and understanding of the factors that contribute to subjective financial distress is necessary. One recent review therefore started with conceptualizing a typology and differentiated material, psychological, and behavioral reactions of the individual cancer patients as a result of subjective financial distress [13]. Yet, a description of how these three domains have been used or compiled into questionnaires and related items is still lacking.

Furthermore, most of the available evidence is from the United States healthcare system [12]. First studies from countries with social insurance-based health care systems indicate need for further methodological research to cover the cancer patients experience and reaction in these health care systems [15–18]. To enable both a better understanding of the underlying construct of cancer-related financial distress and to facilitate the compilation of survey instruments that are adjustable to other healthcare contexts such as third-party-payer systems in Europe, this review systematizes the methods and items that previous studies used for measuring the subjective financial distress of cancer patients. Since a validated test instrument is a prerequisite for robust and comparable results, the present systematic review focuses on the methodology of how questions are used to operationalize the concept of financial distress.

Methods

Search strategy and study selection

We searched PubMed, CINAHL and Web of Science databases up to March 2018 to identify studies that provide data on cancer-related financial distress experienced by adult patients. A manual search was further carried out based on the reference lists of included studies. Different keywords for definitions of financial toxicity as well as cancer and related synonyms were used (see [supplementary Table S1](#), available at *Annals of Oncology* online). We followed the PRISMA guidelines in conducting this review.

Full-text publications of systematic literature reviews, primary observational studies or surveys with cancer patients regardless of tumor entity or employment status were included when available in English or German language. Reported measures of direct (e.g. OOP-cost or deductibles) or indirect treatment-related costs (e.g. loss of earnings) had to be linked with the individuals' perception of its financial situation during or after cancer diagnosis and treatment. A structured and documented data generation via questionnaires or structured interviews was mandatory. Therefore, qualitative studies without structured and published interview guidelines were not considered. Studies on financial consequences of cancer treatment of a household member (especially children) were excluded. No limit was placed on the study setting or publication date.

Data extraction

In the absence of a standardized taxonomy, we define the term financial toxicity as a potential consequence of subjective financial distress experienced by patients due to cancer-related (or

anticipated) direct and indirect treatment costs (see [Figure 1](#)). Since the concept of 'subjective financial distress' is not conclusively defined in neither a broader context nor a disease-specific [13], we analyzed the wording of the included studies and checked whether there was an explanation of the concept of subjective financial distress. Therefore, verbalizations and definitions from the methods and results sections of the included articles were scrutinized. The items used to assess the individual financial distress were extracted from the study reports or, where applicable, from separately published questionnaires. Two authors (JW, RL) independently reviewed abstracts of the studies, and three authors collectively made decisions about whether studies should be included or excluded when there was no consensus on the first review (JW, RL, BS). Two authors (JW, RL) abstracted data from the studies or questionnaires, and all authors reviewed these data and categorized the identified questions regarding the individual responses to financial distress. Any disagreements were resolved by consensus.

Domains of subjective financial distress

[Supplementary Table S2](#), available at *Annals of Oncology* online gives a detailed and comprehensive overview of the questions used in the included studies. Questions were allotted to a classification of six self-developed conceptual subdomains. This classification was based on a typology of three broad domains used by a number of authors [7, 13, 19, 20]. These three domains cover the following aspects: (i) the material conditions that arise from increased direct and indirect costs, (ii) the psychological response as a result of efforts necessary to cope with the increased costs and (iii) the coping behaviors itself that patients adopt to manage their medical care while experiencing increased expenses [13].

We expanded the classification to six subdomains since we learned during the process of allotting questions to domains of financial distress that the preliminary three dimensions were not sufficiently differentiating all aspects (see [Figure 1](#)). We suggest subdividing the domain of *material conditions* into active 'financial spending' (e.g. percentage of health-related spending in relation to household income) and the use up of passive 'financial resources' (e.g. selling property or using up savings). This should enable a better distinction between direct and indirect financial reactions, which seems to be relevant in third-party payer systems with (approximate) full reimbursement of therapy costs. The domain of 'affect' continues to represent the *psychological response* to increased cancer-related expenses (e.g. concerns about current financial situation). To incorporate influences of the surrounding social environment, we propose to rename this domain into 'psychosocial responses'. Last, we suggest subdividing possible *coping behaviors* into three subdomains: 'support seeking' from others (e.g. searching for financial assistance), altering care plans ('coping care', e.g. *cutting back on prescribed medications*) and changes in one's lifestyle ('coping lifestyle', e.g. *reduce leisure activities*).

Results

Study characteristics

Based on 3298 records screened, 41 publications based on 40 studies matched our inclusion criteria (see [Figure 2](#)). Six

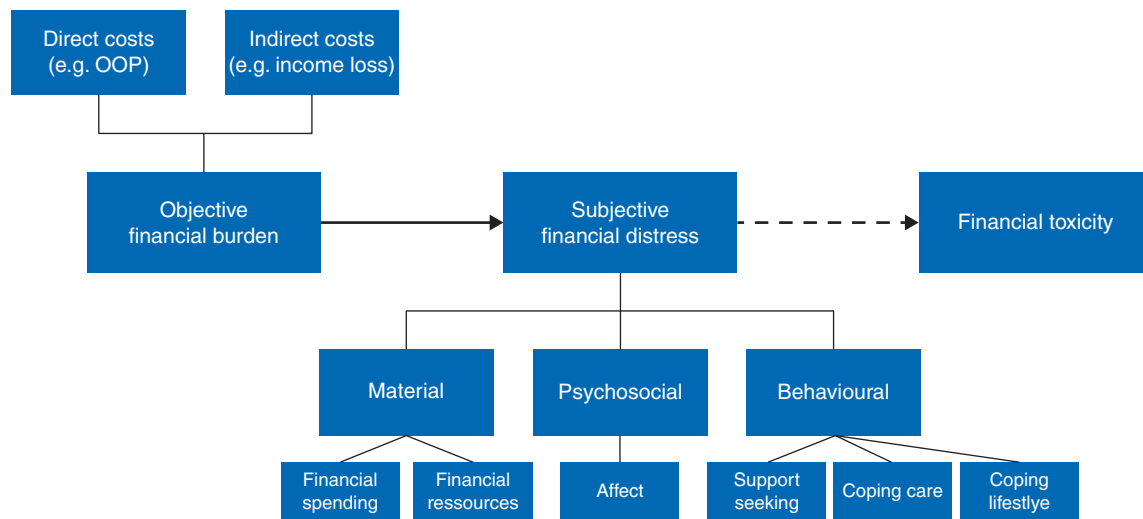


Figure 1. Framework of financial toxicity and related aspects of subjective financial distress.

systematic reviews matching our inclusion criteria were identified that are discussed and contrasted with our results in the discussion section. Detailed information about the included studies can be taken from Table 1. Regarding the number of studies included, it should be noted that two studies are based on the same survey but use different samples and are therefore counted as two separate studies [21, 22].

Most of the included studies ($n=43$) were conducted after 2010, mostly in the United States ($n=30$). There are only four studies from Europe with one study conducted in France [16], one from the UK [23] and two studies from Ireland [17, 18]. The sample sizes range between 73 [24] and a maximum of 9513 participants [25]. Twenty-four of the included studies did not specify the type of cancer patients that were included in the survey. Studies considering a specific type of cancer patients mostly included breast cancer ($n=10$), colorectal cancer ($n=6$), lung cancer ($n=6$) and prostate cancer ($n=6$). Thirty-four studies were quantitative surveys and five studies used qualitative interviews. The time of patient inclusion during their course of disease (e.g. after diagnosis or treatment) varied widely across the identified studies. In four studies [7, 26–28], the study population was already at risk for poverty at study onset (e.g. recruitment through an organization that provides financial assistance to help patients with co-payments, etc.). For a comprehensive overview over the general study characteristics, see [supplementary Table S2](#), available at *Annals of Oncology* online.

Instruments used to measure a patient's subjective financial distress

Most of the studies used self-designed questionnaires to measure subjective financial distress. Fourteen studies were based on eight different pre-existing instruments. These instruments either were designed to measure subjective financial distress or include only a subscale on the financial situation among other items (e.g. HRQOL). Some of them were cancer-specific and others for generic application (Table 2).

Of the four instruments developed specifically for measuring subjective financial distress, three are intended for the indication-specific use in cancer patients (BCFS, COST, SWBS). de Souza et al. [35] first used the relatively new COST measure. Briefly, the COST is an 11-item instrument to measure financial toxicity with a single item on financial spending, 2 items on financial resources and 8 items on the psychosocial response of cancer patients. This instrument was developed in 2014 by de Souza et al. [36] and has recently been validated on United States patients. One study employed the cancer-specific SWBS [39]. It consists of 17 items divided into 2 subscales: material (9 items) and social capital (8 items). While items from the material subscale include questions on financial spending as well as financial resources, the social capital subscale comprise aspects of psychosocial resources such as family support or the person's health literacy. The SWBS was developed to be a subscale of other questionnaires assessing HRQOL but can be used as a stand-alone measure as well [38]. The BCFS, used in one study [30], is a 42-item instrument that asks about crucial aspects of cancer-related economic burden including psychosocial aspects (i.e. changes in motivation, productivity), both aspects of material responses (i.e. changes in income, finding second jobs, selling property, borrowing money, using saving, or missing bill payments), coping behavior (changing economic lifestyle) and OOP expenses (i.e. for insurance, medical care, medicines or alternative treatment and services). The most used instrument was the InCharge Financial Distress/Financial Well-Being Scale [IFDFW, now known as the Personal Financial Wellness Scale (PFW Scale)] used in four studies [4, 32–34]. This instrument is indicated for generic use, measuring solely subjective financial distress with eight items in total, comprising five questions on the psychosocial affect, two questions on financial resources and one item on lifestyle related coping strategies.

Instruments that only include a subscale for financial distress aim at a broader assessment of HRQOL or well-being. The most frequently used disease-specific instrument was the EORTC questionnaire [23, 42, 43]. The EORTC questionnaire includes 30 items measuring the multidimensionality of cancer patients'

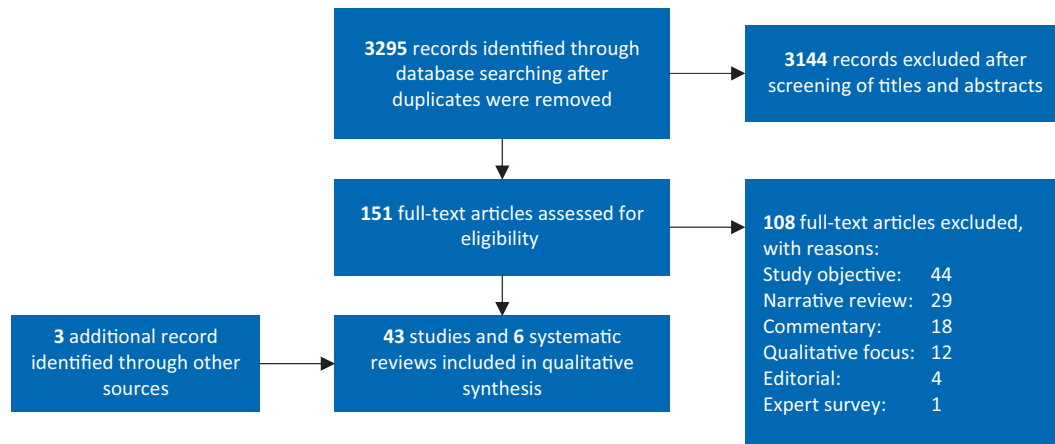


Figure 2. Flow chart of the review process.

Table 1. Summary of general study characteristics	
Country	Frequency
Asia	5
Australia	3
Canada	1
Europe	4
United States	30
Type of cancer	Frequency
Breast cancer	10
Chronic myelogenous leukaemia	1
Colorectal cancer	9
Head and neck cancer	2
Lung cancer	6
Multiple myeloma	2
Prostate cancer	6
Unspecific	24
Wording	Frequency
'burden'	16
'catastrophe'	1
'difficulty'	5
'distress'	12
'hardship'	7
'strain'	3
'stress'	4
'toxicity'	4
'worry'	2
Sample sizes	
Minimum	73
Median	289
Arithmetic mean	838.56
Maximum	9513

HRQOL. The financial difficulty subscale is represented by a single item ('during the past week: Has your physical condition or medical treatment caused you financial difficulties?'). One study measured the financial difficulty of patients using items of the SDI [23]. The SDI consists of 21 items with each of the items covering a different area of potential issues in daily life, such as perceived difficulties with work, residence, finance and planning for

the future [46]. Two of the 21 items refer to cancer-related financial consequences. Two studies used the CanCORS Patient survey to measure the objective financial burden of the cancer patients [49, 50]. This disease-specific survey is designed for patients with lung and colorectal cancer and uses one question on financial resources to capture the individual's reaction to financial burden ('How difficult is it for you to live on your total household income right now?'). One study [45] used the PSQ-18, which assesses how participants feel about the medical care they receive. The 18-item scale includes seven dimensions of satisfaction with medical care, of which 2 items may reflect subjective financial distress ('I feel confident that I can get the medical care I need without being set back financially', 'I have to pay for more of my medical care than I can afford') [44].

Domains and questions to measure subjective financial distress

With regard to the methodology of measuring 'subjective financial distress', three aspects were operationalized quite differently in available studies: (i) the wording used to describe financial distress, (ii) the number of included dimensions and (iii) the corresponding number of questions used within the applied questionnaires.

First, authors used a total of eight different wordings to describe subjective financial distress related to cancer diagnosis and treatment (Table 1). The term 'burden' was used most often ($n = 16$), followed by the terms 'distress' ($n = 12$), 'hardship' ($n = 7$), 'difficulty' ($n = 5$), 'stress' ($n = 4$), 'toxicity' ($n = 4$), 'strain' ($n = 3$), 'worry' ($n = 2$) and 'catastrophe' ($n = 1$), respectively. Secondly, the instrument length ranged from 12 [51] to 130 items [16], including both, items on the subjective perception of financial distress and questions regarding other aspects such as HRQOL, overall survival or other cancer-related issues (Table 3). Thirdly, the number of items specifically focusing on the subjective financial distress ranged from one [43, 50, 57] to 37 [60], with an average of ten questions.

Based on all 352 different questions used in the literature so far, we developed a classification of six relevant subdomains of subjective financial distress. With 34 studies, the majority included financial resources in their survey (Table 3). In order to assess the

Table 2. Pre-existing instruments used to measure subjective financial distress

Cancer-specific		Generic	
Instrument	Development (validation)	Instrument	Development (validation)
Full instrument			
Breast Cancer Finances Survey Inventory	[29]	InCharge Financial Distress/Financial Wellbeing Scale	[31]
The Comprehensive Score for financial Toxicity	[35, 36]	-	-
Socioeconomic Wellbeing scale	[38]	-	-
Subscale			
EORTC QLQ-C30	[40, 41]	Short-form Patient Satisfaction Questionnaire	[44]
Social Difficulties Inventory	[46, 47]	-	-
Cancer Care Outcomes Research and Surveillance Consortium Patient survey	[48]	-	-
			[45]
			[4, 32–34]

material financial burden, both the possibility of active financial spending and usage of passive financial resources need to be distinguished. Half of the studies assessed active financial spending with mostly one or two but no more than six questions. Two studies focused on this issue with 15 [60] or even 19 [23] related questions. The number of items regarding the use of passive financial resources ranged from one item to a maximum of 16 [60]. Psychosocial aspects were only considered in 23 studies. The questions used mainly reflect the perception of stress as a result of financial constraints as well as related fears. Only three studies focused on the assessment of psychosocial aspects asking more than five questions [16, 37, 56], while most of the studies included just one item asking whether patients worry about their financial situation. In contrast, the study by Barbaret et al. [16] exemplifies the possible range of psychosocial reactions. Besides questions on the relation of financial restrictions and stress experience (e.g. 'Has the financial cost of treating your cancer caused you or your family distress?'), perceived financial distress is also captured in relation to typical dimensions of HRQOL (e.g. 'I have more financial distress than physical distress'). Captured behavioral changes includes three different aspects: 'seeking support' from others, altering care plans ('coping care') or changes in one's lifestyle ('coping lifestyle'). Most studies focused on the need to alter care plans (what is uncommon in third-party payer health care systems), the need for support seeking, e.g. from financial advisors or family members, is less studied. Just two studies included items on all three dimensions of behavioral changes [30, 32].

Quantifying data on subjective financial distress

While eight studies do not define whether or how they processed data on subjective distress, other tried to quantify and grade results on the experience of financial distress (Table 2). Methodological approaches for quantifying financial distress are very heterogeneous, as they differ in both, the types of questions that are applied and whether scales are used to quantify the amount or level of subjective financial distress. Underlying scale types were similar in all included questions, including (i) scaled questions (e.g. Likert-scales), (ii) dichotomous questions and (iii) multiple-choice questions or combinations of different scale types (Table 4). When the data were used for quantification, both scores where multiple scales are transformed into a composite value, or threshold values that indicate the presence of subjective financial distress if a certain score value is exceeded, or a minimum number of conditions are met, were used.

Three out of 19 studies that applied a 1D Likert-scale used the EORTC QLQ-C30, in which a single item is answered on a 4-point scale. On this scale, only four scores are possible: 0, 33.33, 66.67 and 100 with a higher score indicating a greater level of financial difficulty [23, 42, 43]. Four studies that applied multi-dimensional Likert-scales calculated a score and then reported a threshold for subjective financial distress or reported several thresholds to distinguish between different degrees of severity of subjective financial distress [32, 33, 37, 49]. Both heuristic and data-driven approaches (e.g. deviation from the median) were used to define such thresholds. An example is the study of Huntington et al. [37] that applied the COST instrument, which

Table 3. Reported aspects of and reactions to subjective financial distress

Study	Questionnaire available ^a	Items on financial distress	Number of items per domain					
			Material		Psycho-social	Behavioral		
			Financial spending	Financial resources	Affect	Support seeking	Coping Care	Coping Lifestyle
Abel et al. (2016) [52]	Yes	10	1	5	–	–	1	3
Azzani et al. (2016) [53]	No	n.s. ^b	–	(6)	(1)	(1)	–	–
Barbarett et al. (2017) [16]	Yes	19	2	1	13	–	3	–
Bestvina et al. (2014) [4]	No	11	–	2	5	–	3	1
Cagle et al. (2015) [54]	No	10	2	7	–	1	–	–
Chan et al. (2013) [55]	No	7	3	1	1	1	1	–
Chino et al. (2014) [45]	No	2	1	1	–	–	–	–
Delgado-Guay et al. (2015) [56]	Yes ^b	4	–	–	4	–	–	–
de Souza et al. (2014) [35]	Yes	11	1	2	8	–	–	–
de Souza et al. (2017) [36]	Yes	11	1	2	8	–	–	–
de Souza et al. (2017) [24]	No	n.s. ^b	(1)	(4)	–	–	(1)	–
Ell et al. (2007) [27]	No	5	1	4	–	–	1	–
Fathollahzade et al. (2015) [33]	Yes ^b	8	–	2	5	–	–	1
Fenn et al. (2014) [57]	No	1	–	1	–	–	–	–
Goodwin et al. (2013) [58]	No	n.s. ^b	(1)	–	(1)	–	–	–
Gordon et al. (2007) [59]	Yes	6	3	1	–	1	–	1
Gordon et al. (2015) [60]	Yes	37	15	16	2	1	3	–
Gupta et al. (2007) [43]	Yes ^b	1	–	1	–	–	–	–
Huntington et al. (2015) [37]	Yes	11	1	2	8	–	–	–
Jagsi et al. (2014) [61]	No	n.s. ^b	–	(5)	–	–	(1)	–
Jan et al. (2015) [25]	No	n.s. ^b	(2)	–	–	–	–	–
Kent et al. (2013) [62]	No	n.s. ^b	–	(1)	–	–	(3)	–
Khera et al. (2014) [39]	Yes	20	6	8	1	–	5	–
Kodama et al. (2012) [63]	Yes	5	1	1	1	–	2	–
Longo et al. (2006/2007) [64, 65]	No	n.s. ^b	(4)	–	–	–	–	–
Meeker et al. (2016) [34]	Yes ^b	11	–	(4)	(5)	(1)	–	(1)
Meisenberg et al. (2015) [32]	Yes	23	4	3	5	4	5	2
Meneses et al. (2012) [30]	No	14	(1)	(9)	–	(1)	(1)	(2)
Nipp et al. (2016) [26]	No	n.s. ^b	–	(4)	–	–	(3)	(1)
Pezzin et al. (2009) [66]	No	n.s. ^b	(1)	–	–	–	–	–
Pisu et al. (2015) [49]	No	3	–	(2)	–	–	–	(1)
Regenbogen et al. (2014) [21]	No	7	2	3	–	–	1	1
Rogers et al. (2012) [23]	No	24	19	2	2	–	–	1
Shankaran et al. (2012) [51]	Yes	12	4	6	–	–	2	–
Sharp et al. (2013) [17]	No	3	–	2	1	–	–	–
Sharp et al. (2016) [18]	No	3	1	1	1	–	–	–
Veenstra et al. (2014) [22]	No	8	2	3	1	–	1	1
Whitney et al. (2016) [67]	Yes ^b	5	1	2	1	–	–	1
Yabroff et al. (2016) [68]	Yes	5	2	2	1	–	–	–
Zafar et al. (2013) [7]	No	24	–	4	1	–	16	3
Zafar et al. (2015) [50]	No	1	–	1	–	–	–	–
Zucca et al. (2011) [42]	Yes ^b	4	1	3	–	–	–	–
Zullig et al. (2014) [28]	No	n.s. ^b	–	–	(1)	–	(5)	(1)

^aAlthough the original questionnaire was available only in 15 out of 40 studies, information on the dimensions used and questions asked could be retrieved from either the methods or result section of all the included studies.

^bWhen the questionnaire is not available, we try to derive questions on financial hardship from the methods section of the paper. As we cannot be sure to quantify the correct number of questions, we count this as “n.s.”. Nevertheless, we try to summarize aspects of and reactions to financial hardship from results presented in the corresponding paper and list them in brackets.

Table 4. Scales for measuring subjective financial distress and their quantification

Type of scale	Quantification	N
Scaled question (e.g. Likert-scale)	1D with threshold	19
	Multidimensional with score	4
	Not defined	2
Dichotomous question	1D with threshold	1
	Multidimensional with score	7
	Not defined	2
Multiple-choice question Combination	Stand-alone	0
	Dichotomous questions and multiple-choice	1
	Likert-scale and dichotomous questions	3
	Likert-scale and multiple-choice	1
	Likert-scale and dichotomous and multiple-choice	1

records financial distress on an 11-dimensional Likert-scale and provides a score ranging from 0 to 44 indicating the extent of ‘financial toxicity’. The lower the score, the worse is the individual’s financial toxicity. Of the studies using dichotomous items, Kodama et al. [63] applied a single dichotomous question (‘Do you feel the financial burden of your medical expenses?’) to measure subjective financial distress. Eight studies that asked more than one dichotomous question defined financial distress as being existent if a certain threshold of conditions is met [21, 22, 24–26, 54, 67, 68] or stated multiple thresholds on different scales, of which at least one has to be satisfied to meet the definition of subjective financial distress.

Discussion

Cancer diagnosis and treatment is associated with physical, psychological and financial burdens in patients. While physical and psychological strain is documented and increasingly addressed with supportive therapy [69] and psycho-oncological support in a systematic way, there is only scarce data on the perception of financial distress and its effects on patients in general—and even less with regard to patients in third-party payer health care systems [70, 71]. While it is commendable that the number of publications on this topic is now on the rise, one major result of this systematic review is that there is a large variation and no consistency in the understanding of *item domains* describing subjective financial distress, and thus a huge variety of *questions* used to measure this issue. In the short term, this has also led to a discordant use of *terminology*. In most studies evaluating the negative personal financial impact of cancer care, the measure of financial distress is not clearly stated nor is the underlying construct validated. It is therefore not surprising that data on subjective financial distress have not yet been *quantified* in a standardized way. In the long term, however, the lack of standardization in measurement also interferes or even prevents the planning and implementation of consolidated measures for early detection and avoidance of financial burdens. We will discuss this

heterogeneity and suggest further steps for consolidating research and potential use of our results.

To clarify the terminology, we suggest the following definition based on our review: ‘financial toxicity’ is the possible outcome of perceived ‘subjective financial distress’ resulting from ‘objective financial burden’. Thereby, objective financial burden refers to direct and indirect cancer-related costs since this concept is well established in health economic analysis despite some critique as to the limitations in the use of objective definitions [72]. Although the wording ‘financial toxicity’ has some appeal because oncologists understand the analogy to other treatment-related side-effects such as nausea or vomiting we should keep in mind that the analogy is questionable as financial difficulties are not always fateful, but the consequence of social or private circumstances in the past.

Possible domains that describe the subjective financial distress have not yet been well established. Based on a broader classification of three dimensions [13], we have identified in total six more precise subdomains that explain perceptions of and reactions to financial distress. While eight different pre-existing instruments were used, most of the questionnaires were self-designed and offer limited to none comparability. The two most frequently used questionnaires are the cancer-specific EORTC questionnaire and the InCharge instrument, indicated for generic use. Both instruments are brief and do not cover all six identified domains of subjective financial distress. However, the EORTC or other, shorter and validated instruments may be used as rough screening tools. Since it is frequently used in pivotal studies of new drugs, it could, e.g. be used to identify cancer indications with a particularly high risk of financial toxicity for cancer patients. A longer instrument reflecting all possible relevant domains of financial distress could then be used within these groups consecutively. In a post hoc analysis, Perrone et al. [14] recently pooled data on subjective financial distress from 16 prospective studies using the EORTC in Italy. Owing to general limitations of observational studies and the accompanying post hoc analysis, generalizability of these study results remains unclear [71]. But also in clinical practice, shorter instruments may be used as an early detection tool during hospital admission to offer counseling services.

The COST measure [36] was validated for measuring financial distress in cancer patients in the United States. However, due to different socio-political conditions, it can be expected that patients in the United States and Europe differ in their experience of financial effects related to cancer diagnosis and treatment. First, due to uniform health-care coverage by social insurance, OOP medical expenses seem not to be that relevant to EU cancer patients since co-payments are capped and supported by social welfare offices in most countries. Secondly, in Europe workplace compensation programs are more prevalent and more comprehensive than in the United States. While in the United States, due to a lack of general security systems, private assets must compensate the loss of income in most cases, in European social security systems other compensation benefits such as sick pay or reduced pension payments through early retirement play a major role. In Europe, most countries provide paid sick leave for at least some weeks. While this might still not be enough, the United States has by and large no statutory mandate for such regulation [73]. In order to assess the influence of a cancer

disease on financial distress, questions relating to earning capacity must therefore be given greater consideration in the European context.

Our six-domain classification of item dimensions allows for a detailed overview of the main research areas and thus facilitates the transfer of the items developed so far to the specifics of the European Health care delivery system. We have shown that questions were mainly asked about material reactions such as using financial resources. Psychosocial aspects, such as perceived impact of financial distress on a person's emotional well-being and social context, were less considered. We have further suggested three different subdomains of coping behavior as we assume each subdomain having different implications on measuring reactions to financial distress. Treatment noncompliance, being an example of the coping care subdomain, probably has direct effect on clinical outcomes [74], whereas the seeking of support or the alteration of one's lifestyle does not affect clinical outcomes directly, although it might still reduce quality of life [75]. Within these different behavioral reactions, strategies to alter care plans were surveyed in most studies, while strategies to alter the lifestyle or to seek emotional or specialized support were only asked in a few studies. Yet, the individual adaptation of treatment plans to financial capabilities is more important in privately financed health care systems, other dimensions such as support seeking may play an important role in social insurance-based systems [76]. Hence, we identified the need for an instrument applicable to countries with universal healthcare. Development should start with a systematic appraisal of domains of the construct to be surveyed. These domains should be based on qualitative research in the respective country and can additionally be taken from existing instruments as shown in our review.

Last, we examined how data on subjective financial distress has been processed to quantify distress using scores or thresholds. Whether scores or threshold values are to be calculated based on this data depends on the goal with which the data is collected. Several valuable applications can be conceived, comparable to other patient-reported-outcome measures such as HRQOL:

Monitoring the financial status of patient groups and their individual perception of subjective financial distress at different moments in time, e.g. diagnosis, curative or palliative treatment, survivor care.

Evaluation and audit of health care, by measuring changes in financial status in individual patients and in groups of patients.

Assessing the seriousness of conditions at different moments of time ('early detection').

Tailoring of information and counseling need.

Systematic reviews generally highlight the need for consistent scales to evaluate financial distress associated with cancer (see [supplementary Table S3](#), available at *Annals of Oncology* online). To our knowledge, this is the first review that aims at compiling and systematizing the constructs, items and scales used so far. Yet, our review has some limitations. Despite the use of multiple databases, we were unable to capture every relevant article because of different indexing used by the databases and the inconsistent terminology used to define financial toxicity or financial distress. To help minimize this limitation, we hand-searched the

reference lists for each article for any additional studies that were not captured in the initial electronic search process. Data extraction was standardized and carried out by at least two authors. However, there still may be some subjectivity in our descriptive classification of items used.

In summary, as we welcome the fact that the topic of financial toxicity is becoming increasingly relevant and that numerous studies are being initiated, we also see shortcomings due to a lack of consensus on a standardized instrument, such as the poor comparability of study results. There is a need to join efforts to develop a common understanding of the concept of financial toxicity and related subjective financial distress. We encourage using the identified six domains (i) active financial spending, (ii) use of passive financial resources, (iii) psychosocial responses, (iv) support seeking, (v) coping with care or (vi) coping with one's lifestyle to further develop survey instruments and adjust them to different health systems. Practically, a discussion on item domains and taxonomy could be coordinated by the EORTC-group, as they already have experience in developing cancer-specific survey tools, such as the EORTC QLQ-C30, that constitutes an important contribution to the assessment of quality of life of cancer patients [40]. In addition, discussions could be initiated with ESMO on whether questions on the subjective financial distress should also be included in the ESMO-Magnitude of Clinical Benefit Scale to enable a better understanding of new treatment options and their relative financial implications to patients.

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