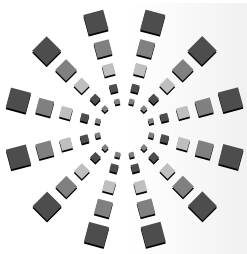

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Financial Toxicity in Adolescents and Young Adults With Cancer

A Concept Analysis

KEYWORDS
Adolescents
Concept analysis
Financial toxicity
Quality of life
Survivorship
Young adults

Background: A cancer diagnosis as an adolescent and young adult (AYA) poses exceptional challenges, including potential greater financial toxicity than older survivors experience who have had more time for career establishment and to build financial assets. Costs to patients have increased more than the past decade; prospects for AYA long-term survival have also increased. A better understanding of what financial toxicity is, how it presents, and the immediate and longer-term implications for AYAs is needed. **Objective:** The aim of this study was to analyze the concept financial toxicity in AYAs diagnosed with cancer. **Methods:** We used Rodgers' evolutionary method and articles published between January 2013 and December 2020. **Results:** We identified key antecedents, attributes, and consequences of financial toxicity in AYAs and review its related terms that have often been used as surrogate terms. Attributes were financial burden, financial distress, and competing financial pressures. Consequences were mostly adverse and persistent and included engaging in various financial problem-solving behaviors, material hardship and poor financial well-being, and deteriorated quality of life. **Conclusions:** Results of this analysis clarify financial toxicity and provide guidance for a conceptual framework in the context of AYA cancer survivorship. Its consequences in AYAs with cancer are profound and will continue to evolve over time with changes in health systems and the economy. **Implications for Practice:** Oncology nurses should understand the attributes and consequences of financial toxicity for AYAs throughout the cancer trajectory. Future research on financial toxicity should extend across AYAs living with other chronic illnesses and cancer survivors in other age groups.

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Introduction

Adolescent and young adult (AYA) cancer survivors (ie, those diagnosed between the ages of 15 and 39 years through end of life)[1] typically require intensive multimodal cancer therapy and supportive care, followed by a period of monitoring for recurrent disease and long-term complications that can arise from treatments.[2] Efforts to cure or control cancer contribute to financial toxicity, a treatment-related consequence gaining increasing global attention. Across cancer types, financial toxicity may result in suboptimal coping and poorer quality of life as compared with AYAs who do not experience financial toxicity.[3] Treatments to cure or control cancer have financial costs that include out-of-pocket payments for cost sharing (eg, deductibles), uncovered treatment-related expenses, and lost income and productivity due to treatment-related employment disruptions and symptoms such as fatigue. The financial costs associated with treatment are further protracted by the need for regular follow-up to monitor for disease recurrence and to identify and manage adverse effects of treatments.

The Concept of Financial Toxicity

Since being applied to cancer populations in 2009[4] and then illuminated in 2013,[5] financial toxicity has been used in reference to financial burden experienced by individuals with chronic illnesses and their caregivers. However, we have not yet captured the breadth of the phenomenon, its consequences, and effective ways of mitigating this problem for cancer survivors and their families and/or caregivers at various phases across the illness trajectory.[5,6]

Globally and across various health service delivery models, healthcare systems and oncology professionals are being called to address both the rising costs of healthcare and the extent to

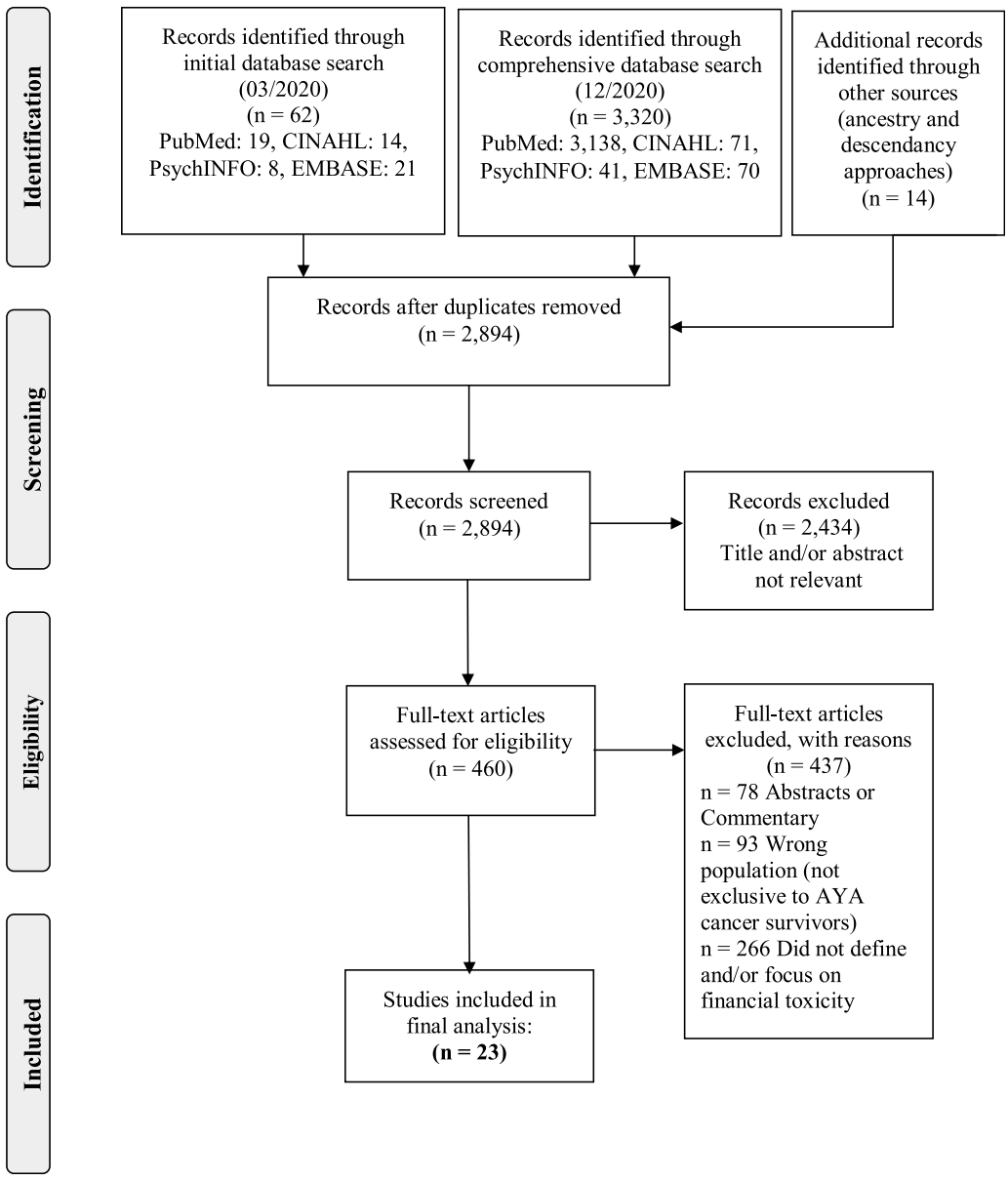

Figure 1 ■ PRISMA (Preferred Reporting Items of Systematic Reviews and Meta-analysis) flowchart.

which those costs are passed on to generate financial toxicity.[7,8] Recent systematic reviews on financial toxicity in patients with cancer[8–10] cite the lack of a clear definition and distinctions between financial toxicity and terms such as financial burden, distress, and hardship as major limitations for advancing this area of science[11] including through collaboration among economists, cancer epidemiologists, cancer care delivery researchers, and oncology clinicians, among others.[9] To the best of our knowledge, financial toxicity induced by the diagnosis and treatment of cancer or any other chronic health problem has not been subjected to formal concept analysis.[11]

Further, consensus is lacking on how financial toxicity presents in specific cancer populations, particularly among AYA survivors, who, some argue, likely experience greater financial toxicity than older individuals living with cancer.[12–14] Clarifying the concept through formal concept analysis may assist in identifying appropriate timing and targets for interventions to alleviate financial toxicity for AYA cancer survivors. Therefore, the purpose of this study is to analyze the concept financial toxicity in the context of AYA cancer survivorship.

■ Methods

Design

Concept analysis is a philosophical inquiry that involves strategic analysis and synthesis of the literature to elucidate concepts, distinguish between related concepts, and build grand and more practical theories[15] to advance science.[16] Unlike integrative or literature reviews, in Rodgers' evolutionary method,[16] the contextual basis comes before (antecedents) or as a result of (consequences) the concept.[17] We selected Rodgers' evolutionary method because financial toxicity is a dynamic concept that will evolve over time with advances in cancer therapeutics, changes in policies at multiple levels, and consequent to historic events such as the coronavirus disease 2019 (COVID-19) pandemic.[16]

Sample Selection

The primary author (L.V.G.) searched computerized databases, with the assistance of an experienced health sciences librarian, to identify peer-reviewed articles published in English between January 2013 (introduction of the term *financial toxicity*)[5] and December 2020. The initial search captured 62 articles about the population (AYA cancer survivors) and the concept (financial toxicity).

Next, the primary author used ancestry (checking reference lists for past studies) and descendancy (checking where early articles were published) approaches to identify additional search terms[18] to support the background of the analysis and identify convergence in the literature.[16] The second database search in April 2020, then rerun in December 2020, resulted in an additional 3320 articles (Figure 1, Table 1). The final step of the search process included a review of both national cancer and AYA-specific cancer websites and recent work by scientists with expertise in financial toxicity.

The primary author used Covidence, a browser-based software, for article management. After duplicates were removed, the first round of screening included review of articles by title and abstract, followed by review of the article text to assess for eligibility. Articles were eligible for inclusion in the concept analysis if (*a*) the study sample included adolescent and/or young adult cancer survivors, and (*b*) financial toxicity, or a related term, was the primary independent or dependent variable. Articles including AYA cancer survivors diagnosed during infancy or childhood (ages 0-16 years) were not eligible. Articles reporting results with a broader range of ages in their sample (eg, younger cancer survivors aged <65 years) were included if the article discussed findings specific to the AYA subsample. Theory, opinion pieces, and editorials contributed to the background and discussion, but not to the final sample of articles analyzed.

Table 1 • Database Searches

Databases	Search	Date	Search String
PubMed, CINAHL (Nursing and Allied Health), PsycINFO (Psychology), and EMBASE (Biomedical)	Initial	March 2020	((((((adolescent and young adult)) OR AYA) OR young adult) OR adolescent)) AND (((cancer) OR malignanc*)) AND financial toxicit*
	Comprehensive	April 2020 and rerun December 2020	(((((((adolescent* and young adult*) OR (adolescent*)) OR (young adult*)) OR (emerging adult)) OR (AYA)) AND ((cancer) OR (malignanc*))) AND ((((((((((((((burden) OR (calamit*)) OR (catastrophe)) OR (consequence)) OR (difficult*)) OR (distress)) OR (hardship)) OR (loss)) OR (sacrifice)) OR (strain)) OR (stress)) OR (vulnerabilit*)) OR (well-being)) OR (worr*)) OR (toxicit*)) AND (financial))) AND ((((((((((((((burden) OR (calamit*)) OR (catastrophe)) OR (consequence)) OR (difficult*)) OR (distress)) OR (hardship)) OR (loss)) OR (sacrifice)) OR (strain)) OR (stress)) OR (vulnerabilit*)) OR (well-being)) OR (worr*)) OR (toxicit*)) AND (economic))

Table 2 • Evidence Table of Articles Selected for Analysis

Author	Purpose	Country	Sample	Design	Measure	Main Finding Regarding Financial Toxicity
Altice et al (2016)[19]	"Inform future research in cancer survivorship and intervention development in order to minimize the effects of financial hardship" (p.2)	USA	N = 45 studies (from 1990 to 2015) **Ages:** 18–39 y (in 80% of studies) **Cancer type**: all **Trajectory**: all	Systematic review	Categorized financial hardship measures into: material conditions, psychological responses, and coping behaviors	Younger survivors (<40 y) had higher rates of bankruptcy than older survivors
Ashing et al (2018)[20]	"Examined demographic characteristics and patient centered outcomes to inform targeted psychosocial oncology care among African American and Latinas young breast cancer survivors (YBCS)"	USA	N = 116 (African American and Latina women) **Ages:** 25–50 y **Cancer type**: breast cancer **Trajectory**: within 1–6 y of diagnosis	Cross-sectional	Income, educational attainment	Financial toxicity directly influenced both access and quality of care and survivorship outcomes
Banegas et al (2016)[21]	"Examined the proportions of survivors who reported going into debt or filing for bankruptcy as a result of cancer, as well as the amount of debt incurred" (p54)	USA	N = 4719 (across ages) n = 1491 (18–44 y) **Cancer type**: all **Trajectory:** all **Data:** Livestrong 2012 survey	Cross-sectional	Measures of financial hardship (including amount of money borrowed, debt incurred, worry about paying bills, types of OOP expenses)	Compared with those who were older, younger survivors, those with lower incomes and public health insurance were more likely to go into debt or file for bankruptcy
Benedict et al (2018)[22]	"Explore the experiences and financial concerns of survivors pursuing family-building through assisted reproductive technology (ART) and adoption" (p1)	USA	N = 46 (81% female) **Ages:** 23–38 y (n = 5 diagnosed <15 y) **Cancer type**: all **Trajectory:** posttreatment with stable disease or in remission **Data:** Samfund grant applications	Retrospective multimethod	Financial information from grant application (eg, household income, liabilities, and debt) and essay responses describing need for financial assistance	One theme identified financial barriers to family-building after cancer
Fidler et al (2019)[23]	"Compare the risk of late effects of therapy between survivors of AYA and childhood cancer and explore 3 critical challenges faced by AYA cancer survivors—fertility and sexuality, psychosocial outcomes, and financial consequences" (p1)	International	n = 11 studies (in review to identify interventions aimed at preventing, diagnosing, or mitigating the impact of late effects in AYA cancer survivors)	Review	Potential earnings, lost productivity, heath care expenditures	Characterization of financial toxicity highlighted as a gap in AYA cancer research

(continues)

Table 2 • Evidence Table of Articles Selected for Analysis, Continued

Author	Purpose	Country	Sample	Design	Measure	Main Finding Regarding Financial Toxicity
Gordon et al (2017)[24]	"Determine the extent of f inancial toxicity among cancer survivors, identify the determinants and how financial toxicity is measured"	International	N = 25 articles **Cancer type:** all **Trajectory:** all	Systematic review	N/A	Being female, younger age, low income at baseline, adjuvant therapies, and more recent diagnosis were associated with financial toxicity
Gupta et al (2020)[25]	"Examine the experience of cancer-related financial stress within the developmental context of emerging adulthood"	USA	N = 52 **Ages:** 18–29 y **Cancer type**: Testicular and hematologic **Trajectory:** Diagnosed <5 y	Qualitative secondary analysis (from 2 studies)	No direct question about financial stress	Financial stress interrupted developmental tasks. Was seen as a benefit for some participants
Guy et al (2014)[26]	"Estimate direct medical costs by examining annual healthcare expenditures and indirect morbidity costs by examining lost productivity associated with employment disability, missed work days, and lost household productivity" (p1025)	USA	Cases: n = 1464 AYAs (15–39 y old) Controls: n = 86 865 adults without a history of cancer (>18 y old) **Cancer type**: All (excluded nonmelanoma and other unknown skin cancers) **Data:** 2008–2011 Medical Expenditure Panel Survey (MEPS)	Case-control cross-sectional	Direct medical costs (source of payment, service type) and indirect costs (employment disability, missed work days, lost productivity)	Compared with adults without cancer history, AYAs with cancer: ↑ annual per person medical expenditures ($7417 vs. $4247); ↑ reporting employment disability, ↑ number of missed work days (as result of illness); ↑ total annual per capita lost productivity ($4564 vs. $2314)
Meernik et al (2020)[27]	"To provide insight for improvement in care for young adults diagnosed with cancer (YADC), by identifying underemphasized outcomes that strongly matter to YADC and the gaps in care that may limit achieving these outcomes for this unique and vulnerable population" (p1)	USA	N = 27 AYAs **Ages:** 25–39 y **Cancer type:** all **Trajectory**: all	Qualitative	No direct question about finances in interview guide	Financial toxicity was an identified theme, capturing life goals and family plans derailed as a result of participant's financial situation
Jones et al (2020)[28]	"Examined age differences in financial distress in hematopoietic cell transplant survivors and whether these differences result from measurement bias, more financial barriers to care, or an overall higher level of distress" (p1)	USA and Canada	N = 1135 (across ages) n = 117 (18–39 y; 59% female) **Cancer type:** hematologic **Illness trajectory:** 2–10 y posttransplant	Cross-sectional (baseline data from RCT)	Cancer and Treatment Distress Scale— financial distress subscale	AYAs reported more financial and overall distress than older (65+ y) adults.

(continues)

Table 2 • Evidence Table of Articles Selected for Analysis, Continued

Author	Purpose	Country	Sample	Design	Measure	Main Finding Regarding Financial Toxicity
Kaddas et al (2020)[13]	"Examined differences in financial toxicity among individuals diagnosed with cancer as AYAs by age group at diagnosis: 15–25 and 26–29 y" (p106)	USA	N = 52 (~54% female) **Ages:** 15–39 y (n = 24 15–25 y; n = 27 27–39 y) **Cancer type**: all **Illness trajectory: a**ll	Cross-sectional	240-item survey including COmprehensive Score for Financial Toxicity (COST)	Greater financial toxicity was seen in older AYAs (18.22 vs. 24.84, $P = .02$)
Kaul et al (2017)[29]	(1) "Examine cost-related medication nonadherence among survivors of AYA cancer versus a comparison group of individuals without cancer" (p2726) (2) "Examine demographics and health-related factors associated with medication nonadherence" (p2727)	USA	Cases: n = 953 AYAs (15–39 y) Controls: n = 953 comparison group (using propensity scores) **Cancer type**: all (excluded nonmelanoma and other unknown skin cancers) **Trajectory**: all **Data:** 2013–2015 National Health Interview Survey	Case-control cross-sectional	Cost-related medication nonadherence (skipped medication doses, took less medicine, or delayed filling a prescription to save money)	AYAs with cancer more likely report nonadherence; not affording medication; asked physician for lower cost medication; and using alternative therapies to save money compared with insured AYAs, uninsured reported: nonadherence and greater mental distress
Ketterl et al (2019)[30]	"Evaluate the impact of cancer-directed treatment on physical and mental impairment of work-related tasks, the need for employment changes, including paid or unpaid time off from work, and the financial toxicity for cancer survivors aged 18 to 39 and their families" (p1909)	USA	N = 872 AYAs **Ages:** 18–39 y **Cancer type:** all **Trajectory**: within 1–5 y from diagnosis and >1 y after therapy completion	Cross-sectional	Physical, mental, financial effects in online survey of patient reported outcomes (specific measures not described; focused on 6 questions)	Radiation associated with ↑ odds of physical impairment ($P < .01$); chemotherapy associated with ↑ likelihood reporting mental impairment of work tasks ($P < .01$) and ↑ likelihood of taking any time off work
Landwehr et al (2016)[31]	"Quantify the financial burden of cancer in YAs" (p863)	USA	Cases: n = 334 YAs with cancer (19–39 y old) Controls: age-matched peers from MEPS (18–44 y) and US census data (<35 y and 25–34 y) **Cancer type**: all **Data:** Samfund grant applications (2007–2013); MEPS and US Census	Case-control cross-sectional	Financial indicators (credit card debt, total liabilities, monthly income and expenses, monthly medical and student loan expenses)	Compared with US census data, YAs with cancer faced: ↓ median income; ↑ OOP expenses; ↓ net worth. Older YAs (30–39 y old) faced worse prefunding financial situations than younger YAs (19–29 y)

(continues)

Table 2 • Evidence Table of Articles Selected for Analysis, Continued

Author	Purpose	Country	Sample	Design	Measure	Main Finding Regarding Financial Toxicity
Macpherson et al (2020)[14]	"Explored the financial resources required for YAs to move forward after cancer treatment" (p1)	USA	N = 104 **Ages:** 17–39 y **Cancer type:** all **Trajectory**: >1 y posttreatment with stable disease or in remission **Data:** Samfund grant applications (2012–2013)	Qualitative secondary analysis	Essay responses describing need for financial assistance	YAs reported several conditions needed to move forward financially after cancer treatment
McNeil et al (2018)[32]	"Aimed to examine the financial impact of cancer for AYAs ages 15 to 25 y and their parent caregivers in Australia, including whether clinical and sociodemographic factors identified in extant literature were associated with these outcomes" (p18)	Australia	N = 196 **Ages:** 15–25 y **Cancer type:** all **Trajectory:** 6–24 mo from diagnosis	Multiple method cross-sectional analysis	Financial burden (Psychosocial Assessment Tool) measured financial impact of cancer and use of income support	>50% reported financial issues as a consequence of cancer. Issues were from direct medical costs, treatment costs, and indirect costs from loss of income
Murphy et al (2018)[33]	"Examined patterns of prescription medication use and polypharmacy in a population-based sample of cancer survivors" (p2850)	USA	N = 5216 (across ages) n = 572 (18–39 y) **Cancer type**: all **Trajectory**: all **Data:** MEPS (2008–2014)	Case-control secondary analysis	Polypharmacy; prescription expenditures	Compared with age-matched controls, YAs were found to have twice the prevalence of polypharmacy
Pearce et al (2019)[34]	"To examine the relationship between employment and financial toxicity by examining the prevalence of, and factors associated with, financial toxicity among cancer survivors" (p10)	The Nether-lands	N = 2931 **Ages:** 18–65 y **Cancer type**: all **Trajectory**: all **Data:** Dutch PROFILES registry	Secondary analysis	EORTC QLQ-C30: "Has your physical condition or medical treatment caused you financial difficulties in the past week?"	Greater odds of reporting financial toxicity in male, younger, married, low socioeconomic status and education, and unemployed participants ($P < .01$)
Perez et al (2020)[35]	"Explore several core topics that affect AYAs' quality of life and that can be challenging to address" (p1)	USA	**Ages**: 15–39 y **Cancer type**: all **Trajectory**: all	Review	N/A	Cost conversation components in discussing financial concerns for AYAs
Salsman et al (2019)[36]	"To discuss the financial impact of cancer among AYAs"	International	**Ages**: 15–39 y **Cancer type**: all **Trajectory**: all	Review	N/A	Common approaches to conceptualizing financial toxicity; identifies financial interventions for AYAs with cancer

(continues)

Table 2 • Evidence Table of Articles Selected for Analysis, Continued

Author	Purpose	Country	Sample	Design	Measure	Main Finding Regarding Financial Toxicity
Tan et al (2020)[37]	"To understand survivorship issues related to work and insurance coverage among Asian AYA cancer survivors" (p2)	Singapore	n = 23 AYA survivors n = 18 healthcare providers **Ages**: 16-39 y **Cancer type**: all **Trajectory**: Diagnosed within 6 mo to 4 y	Qualitative	Interview guide: "Did you face financial issues during and after treatment?"	Work-related challenges are complex and multifaceted. Despite financial safety net (universal health insurance in Singapore), perception of financial burden still present
Thom and Benedict (2019)[38]	"Explore the prevalence and predictors of self-reported financial toxicity among YA cancer patients and survivors, and its impact on psychological well-being, self-efficacy for coping with cancer, and cost-coping behaviors" (p2)	Unknown	N = 140 (79% female; 80% White) **Ages:** <40 y **Cancer type**: all **Trajectory:** all	Cross-sectional	COST	Worse financial toxicity associated with: ↓insurance satisfaction ($r = 0.52$; $P < .001$); ↑ levels of depressive and anxiety symptoms ($r = 0.43$; $P < .001$); ↑ worry ($P < .001$); ↓ self-efficacy in coping with cancer; and skipping or delaying treatment
Thom et al (2018)[39]	"Describe how financial toxicity and the fertility-related side effects of treatment can co-occur among YA cancer survivors and propose steps to alleviate the distress associated with this intersection" (p3284)	USA	**Ages:** 18-39 y **Cancer type**: all **Illness trajectory:** all	Review	N/A	Role of provider to make referrals to financial support services. Recommended interventions in pretreatment and posttreatment settings

Abbreviations: AYA, adolescent and young adult; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; MEPS, Medical Expenditures Panel Survey; OOP, out-of-pocket; PROFILES, Patient Reported Outcomes Following Treatment and Long-term Evaluation of Survivorship; YA, young adult.

Data Source Management

The primary author read through each article twice before extracting data. Then keywords relating to the components of the concept analysis were abstracted from the articles into a predetermined matrix with the following headings: financial toxicity conceptualization, surrogate and related terms, antecedents, attributes, and consequences. The matrix assisted with identifying common themes among the data sources, as well as areas of divergence. Based on this matrix, tables were constructed to highlight the components of the concept analysis.

■ Results

The concept analysis included 23 articles (Figure 1, Table 2). Studies used a range of descriptive designs, including 5 literature reviews.[19,23,24,35,36] Whereas the study samples were predominantly White and female identifying, 1 study[20] was specific to African American and Latina breast cancer survivors. Two articles focused on AYAs with specific types of cancer (hematologic[28] and hematologic or testicular[25]). Fifteen articles focused on AYA survivors living in the United States, whereas 3 included global samples.[23,24,36] Articles spanned various disciplines, including economics, psychology, medicine, nursing, and policy. The results are presented as follows: conceptualization of financial toxicity, surrogate and related terms, antecedents, attributes, consequences, and an exemplar of financial toxicity in AYA cancer survivors.

Conceptualization of Financial Toxicity

Financial toxicity literature spanned age groups/developmental stages, cancer types, and illness phases within the AYA population (Table 2).[30,31,36–39] Identified gaps included no indication of how or when an individual is determined to have financial toxicity or whose role it is to make that determination. Some articles focused on supportive care needs highly relevant to AYAs, including fertility preservation.[22] Two articles highlighted the relationship between employment and financial toxicity,[30,34] whereas others described financial toxicity in light of escalating costs (eg, higher prices of new classes of therapeutic agents and targeted therapy).[40,41]

As no universally accepted definition of financial toxicity exists,[8] several definitions were identified in the literature (Table 3). Building on the work of Carrera et al,[40] we offer the following definition of financial toxicity: the demands of cancer care and treatment on personal finances create financial burden, driving financial distress, which leads to financial problem-solving behaviors, material hardship, poor financial well-being, and deteriorated quality of life.

Surrogate and Related Terms

Surrogate terms are words other than the concept of interest that express the same concept, whereas related terms do not fully encompass the same attributes as the concept.[16,17] No surrogate terms were identified. Related terms included financial/economic difficulty, burden, devastation, distress, hardship, strain, stress, calamities, consequences, loss, vulnerabilities, and well-being. Salsman et al[36] described multiple related terms in their review of the financial impact of cancer on AYAs, and although several of the terms overlap, an indication of their appropriateness as related terms, they do not fully capture all the phenomena represented by financial toxicity. To address this, Table 4 expands on the terms Salsman et al[36] employed and displays the relationship of some related terms to the concept of financial toxicity.

Antecedents

Antecedents include events or themes that are essential for the concept to occur (Figure 2).[16] Antecedents for financial toxicity in AYA cancer survivors included a cancer diagnosis and cancer treatment,[47] regardless of treatment modality (eg, chemotherapy, radiation, surgery).[13,47]

Another antecedent included the theme "precancer financial status." Adolescents and young adults with cancer reported the diagnosis as being unfair and unexpected in relation to their life course and a shock to their financial state.[22] For many AYAs, this was the first time they were dealing with a major illness requiring frequent interaction with the healthcare system.[25] Exceptions might have included AYAs who work in healthcare and thus have better understanding, albeit from a different perspective. Financial status included preillness employment, insurance coverage, out-of-pocket nonmedical costs (eg, student loans, credit card debt, rent), financial resources with monetary value (eg, paid time off, assets that can be liquidated to raise money), and financial and health insurance literacy. Limited sources of social and financial support within the environment prior to one's cancer diagnosis and lack of access to age-based social safety nets as compared with some older adults were also potential causes of financial toxicity.[35] Although other sociodemographic variables are known to exacerbate risk of financial toxicity (including male sex and lower education level), they were not essential for it to occur.

Attributes

Attributes refer to common characteristics of financial toxicity that emerge from the way in which it manifests in real-world conditions (Figure 2).[16] We identified 2 overarching attributes of financial toxicity for AYAs during the active treatment and rehabilitation phases of the cancer trajectory: financial burden and financial distress. A third attribute—competing financial pressures during the AYA period—preexisted and was included alongside cancer-induced financial burden and associated financial distress. The overarching attributes, financial burden and financial distress, are discussed in further detail below.

FINANCIAL BURDEN

Financial burden is a combination of high medical expenditures (payments) relative to income.[31,36] Financial expenditures related to AYA cancer care included both direct and indirect costs, exacerbated by rising healthcare expenditures.[48] Direct costs included out-of-pocket expenditures for hospitalizations, prescription(s) (eg, chemotherapy, immunotherapy), over-the-counter medication(s), outpatient clinical visits (eg, diagnostic and regular follow-up testing, imaging studies, clinical evaluations with other specialty providers), other outpatient cancer treatments (eg,

surgery, radiation), and supportive care services.[40,48] Direct costs also encompassed nonmedical treatment–related costs such as travel expenses and child care. Indirect costs were identified by loss of income and opportunities (eg, unable to accept promotion or new job, lost productivity).[5,19,23,24] Reduced income was often a result of lost earnings related to unpaid time away from work or withdrawal from full-time professional training for which one is paid a stipend (ie, absenteeism, which may include paid personal days, vacation, or sick time) and/or persistent or new-onset unemployment.[24,34,46] One study using Medical Expenditure Panel Survey data reported greater lost work productivity among AYA survivors than "older" cancer survivors.[26] As such, loss of income, such as unemployment, may be the most important socioeconomic predictor of financial toxicity and a "hidden driver" of financial toxicity.[46]

Adolescents and young adults accumulated medical expenses and reported reduced income due to cancer-related work disruptions, which worsened financial burden. Compared with peers

Table 3 • Existing Definitions and Components of Financial Toxicity

Author and Year	Definition of Financial Toxicity	Components of Financial Toxicity	Area
Carrera et al (2018)[40]	"Unintended—but not necessarily unanticipated—objective financial burden on and subjective financial distress experienced by patients with cancer as a result of their treatment, particularly as they relate to newer classes of drugs and concomitant health services" (p154)	Financial burden, financial distress	Health (medicine)
Chan et al (2019)[41]	"Financial distress/hardship associated with cancer and its treatment" (p646)	Financial distress, financial hardship	Health (nursing and medicine)
Chi (2017)[42]	"Objective and subjective measures of financial strain that many people with cancer face as a result of costly care and treatment" (p1)	Objective and subjective financial strain	Social work
de Souza et al (2014)[43]	"Objective financial consequences of cancer, as well as the subjective financial concerns" (p476)	Financial consequences, financial concerns	Health (medicine)
Desai and Gyawali (2020)[11]	"Detrimental effects of the excess financial strain caused by the diagnosis of cancer on the well-being of patients, their families and society" (p1)	Detrimental effects, financial strain	Health (medicine)
Fessele (2017)[44]	"Increasingly frequent problems resulting from high medical payments combined with lower income because of job interruption" (p762)	High medical payments, lower income	Health (nursing)
Jones et al (2020)[28]	"Any negative effect or its treatment on a patient's finances" (p1)	Negative effect on finances	Health (medicine)
Lentz et al (2019)[3]	"Adverse impact of a cancer diagnosis on a patient's financial well-being resulting from direct or indirect costs" (p1)	Financial well-being, direct or indirect costs	Health (medicine)
Pearce et al (2019)[34]	"Both the financial consequences of cancer and its treatment, as well as the resulting concern or distress" (p10)	Financial consequences, financial concern, financial distress	Economics
Salsman et al (2019)[36]	"Adverse economic consequences to patients resulting from treatments and disease; conveys the harmful personal financial burden faced by patients receiving cancer treatment" (p3)	Economic consequences and financial burden	Health (medicine)
Thomas et al (2019)[10]	"Financial burden and resulting financial distress a patient or caregiver experiences that is associated with cancer and its treatment" (p5)	Financial burden, financial distress	Health (nursing)
Zafar and Abernethy (2013)[5]	Objective financial burden and subjective financial distress	Financial burden, financial distress	Health (medicine)

Table 4 • Related Terms, Definition, and Relationship to Financial Toxicity

Term	Definition	Comparison to Financial Toxicity
Financial/economic *burden*	"A relatively objective measure of personal financial status, defined as the ratio of total out-of-pocket spending on health-related costs (medical and nonmedical expenses) to total household income"[9(p3)]	An attribute of financial toxicity
Financial/economic *distress*	"A subjective measure of the impact of financial burden on patient well-being; captures the affective experience and reflects the extent of worry, anxiety, or anguish about financial burden, experienced, or anticipated"[36(p3)]; "refers to the emotional effects of high cancer costs including worry about one's financial future and distress over increased financial toxicity"[28]	An attribute of financial toxicity
Financial/economic *hardship*	"Difficulty one might experience in attempting to secure financial resources; can be expressed in domains such as finances, health, and food (eg, difficulty paying bills, ongoing financial stress, medication reduction to reduce cost, food insecurity)"[36(p3)]	Financial hardships are also an attribute of financial toxicity. Has been used synonymously with financial burden
Financial/economic *stress*	"The psychological burden of illness-related expenditures"[25]	A surrogate term of financial/economic distress, and an attribute of financial toxicity
Financial/economic *strain*	"A subjective measure characterizing how an individual perceives his or her overall economic resources relative to obligations and needs"[45]	Can be a measure, or aspect, of financial hardship; or synonymous within financial burden, thus is an attribute
Financial/economic *well-being*	An overall assessment of one's financial status[46]	Antonym; financial toxicity is the absence of financial well-being

without a history of cancer, AYAs with cancer reported higher out-of-pocket expenditures for healthcare-related costs, in one study, paying an estimated excess of $5420.[26] A decreased ability to work[13,14] meant the AYA cancer survivor needed to confront education and work expectations and determine feasibility to continue, including whether their employer allows for paid work leave.

From their midteens through late 30s, AYA cancer survivors had competing financial pressures, including student loans,

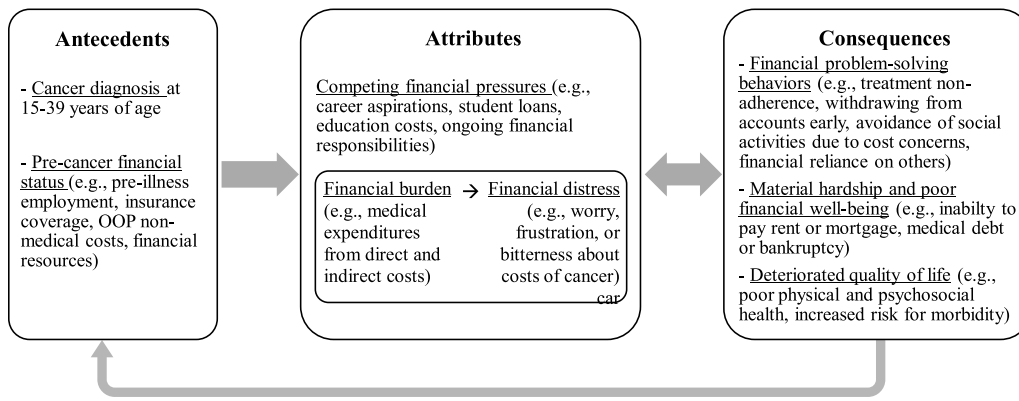

Figure 2 ■ Antecedents, attributes, and consequences of financial toxicity in AYAs with cancer. The arrow from "consequences" to "antecedents" illustrates that the consequences of a primary cancer diagnosis would become antecedents in the event of recurrence or progression. Abbreviation: OOP, out-of-pocket.

tuition costs, low hourly wages, and early career entry-level salaries.[13,22] The developmental tasks of emerging adulthood (approximately ages 18–29 years within the AYA period) included completing education, establishing independence, and managing relationships.[25] Further, older AYAs did not have opportunities to accrue financial security or stability (eg, retirement funds, home equity) compared with AYAs aged 15 to 17 years who were moving toward independence yet typically financially reliant on their parents.[13] In addition, some emerging adults may have started to form their family and have children who depend on them to provide essentials such as food, housing, and health insurance. These increased expenses, compiled with decrease in income, ultimately drove the second attribute of financial toxicity, financial distress.

FINANCIAL DISTRESS

Financial distress was the subjectively reported psychosocial distress due to the preceding financial burden.[40] Adolescents and young adults reported financial distress when considering how spending related to cancer care could be used for other expenses, such as retirement or repaying student loans,[13,36] basic needs (food, housing, clothing, personal grooming), and participation in the leisure and social activities that AYAs typically pursue at this time. Financial distress contributed to poorer health-related quality of life through avoidance of these social activities and healthcare due to concerns about costs. Lastly, financial distress led to AYAs' financial dependence on others, including parents, partners, and/or members of their social network.[14]

COMPETING FINANCIAL PRESSURES

Competing financial pressures for AYAs also affected financial distress, which presented in AYA cancer survivors as worry and guilt about burdening others (eg, partners, parents) with their medical bills.[22] The emotional effects of financial burden included worry about one's financial future.[28] The sense of self-sufficiency and independence that AYAs were attempting to obtain during this period in the life course highlights how developmental tasks can influence financial distress.[14] This is especially salient when, to address cancer's threat to their lives and the associated financial burdens, some AYA cancer survivors had to delay pursuing higher education, forego independent living, and/or ask for financial support through fundraising or online crowdfunding.[14]

The lack of greater disposable income and other accumulated assets in this population contributed to financial distress. For example, AYAs reported frustration and bitterness when they were unable to afford vacations or shopping trips with friends,[25,38] straining social relationships because of their cancer-related financial burden.

These attributes suggested that AYAs may be at greater risk of financial toxicity compared with other age-based cancer populations,[36] related to the unique challenges and developmental stages during which career aspirations, student loans, education costs, ongoing financial responsibilities, and limited income and accumulated monetary assets contribute to financial vulnerability.[49]

Consequences

Consequences (ie, outcomes of financial toxicity)[16] were mostly adverse and persistent among AYA cancer survivors (Figure 2).[46] Consequences included engaging in various financial problem-solving behaviors, material hardship and poor financial well-being, and deteriorated quality of life seen in poorer physical and mental health.

Adolescents and young adults engaged in problem-solving behaviors intended to address the immediate financial problem and control the possibility of further financial problems. However, some behaviors impacted AYAs' adherence to treatment plans.[25,34] Examples included foregoing participation in clinical trials or innovative therapies because of higher costs, not taking or reducing doses of prescribed medications, and skipping treatment appointments and/or follow-up care.[36,48] All of these behaviors have the potential to further existing disparities in cancer outcomes for AYAs. In addition, although some withdrew money from savings or retirement accounts to pay for treatment or follow-up care, AYAs were less likely to have accumulated assets that they could draw from.[24,34] Some AYAs relied on family and friends for financial support, which may contribute to a loss of autonomy during this critical stage of development.[25,36] Another problem-solving behavior included AYAs relying solely on credit cards to pay medical and day-to-day living expenses, paying the minimum amount due, and thus accumulating exorbitant debt related to mounting interest charges.[14,31]

Conversely, a positive benefit from financial toxicity was discussed in one study examining the experience of cancer-related financial stress in emerging adults.[25] These survivors reported receiving financial support from friends, family, workplace, or crowdfunding sites, which provided some sense of financial security. Thus, experiencing financial toxicity offered a new outlook on life, contributing to AYAs' maturity, such as feeling empowered to initiate conversations about costs of cancer following, or throughout, their experience of financial toxicity.

Other broad consequences of financial toxicity were material hardship and poor financial well-being. A secondary analysis using data from grant applications[14] categorized material hardship under "meeting immediate needs," and this included not being able to pay one's rent or mortgage as a result of medical expenditures from direct and indirect costs. A recent review[19] included poorer financial well-being as evidenced by medical debt or bankruptcy. Adults with cancer have an almost 3 times higher risk of bankruptcy compared with patients without a cancer history, which increased the risk of mortality by 79%.[50] Among AYA cancer survivors, this risk of medical debt and bankruptcy is higher.[26,51] Further, financial toxicity among younger survivors may persist years after a cancer diagnosis, thus placing them at risk of long-term, poorer financial well-being than peers without a cancer history.[26]

Psychosocial consequences of financial toxicity were also described in the literature, including higher rates of depression, increased nonspecific psychological distress, and impaired health-related quality of life.[24,52] The negative psychosocial consequences of financial toxicity extended to family and caregivers in younger, adolescent patients.

As described previously, financial burden related to the diagnosis and treatment of cancer must be present for the cancer survivor to experience financial distress. That is, AYAs might look ahead to additional years of surveillance and monitoring and estimate the out-of-pocket expenses that can accrue based on last

year's medical billings. Doing so may, or may not, affect their patterns of saving and spending on social activities over that year, as evidenced by consequences of financial coping strategies, financial well-being, and other quality-of-life domains. Financial toxicity for AYA survivors is thus a dynamic and iterative process, as consequences, such as financial coping strategies or medical debt or bankruptcy, can be antecedents to further financial toxicity and potentially, depending on financial coping strategies, greater risk of unrecognized and/or untreated comorbid conditions, recurrent or progressive disease, and mortality (Figure 2).

Financial Toxicity in AYA Cancer Survivors: An Exemplar

Based on the above understanding, and the inductive technique of Rodgers' evolutionary method, we provide a practical example of financial toxicity in AYA cancer survivors. This identified exemplar is based on the authors' professional and personal experiences with AYA cancer survivors.

At age 22, Jake was diagnosed with Hodgkin lymphoma, for which he received chemotherapy and radiation. A recent college graduate, he had moved to a new city to start his career. His immediate concerns were whether he would survive and how he could afford his treatment, rent, and student loan repayments. He had medical bills from urgent care appointments, laboratory tests, imaging studies, and biopsy that led to his cancer diagnosis. Jake's employer-sponsored health insurance plan had a high deductible. He was unsure whether he should disclose his diagnosis and need for regular treatment to his employer, because he worried he might lose his job and health insurance coverage. Jake had no prior experiences with serious medical illness and did not know how to manage his finances or navigate health insurance and the healthcare system in general.

Prior to initiation of chemotherapy, Jake was offered the opportunity to undergo sperm cryopreservation so that he could eventually have children. He received a foundation grant that covered the initial expenses, but he was required to pay monthly storage costs.

Jake decided to disclose his diagnosis to his employer, with the hope of being able to adjust his work schedule around medical appointments. While his employer accommodated his request, Jake was required to take at least 2 days off without pay every other week to receive treatment, which drastically reduced his income. He delayed student loan repayments while in treatment, and the accumulating interest worsened his indebtedness. To minimize risk of infection, Jake avoided public transportation and spent more on private transportation to work and medical appointments. He ordered more take-out food, because he was too fatigued to shop for groceries and cook. About midway through treatment, Jake began to experience extreme nausea but did not take antiemetics because he could not afford to fill the prescription.

Jake's savings were depleted. He worried whether he could afford his apartment. He was unable to afford social activities with friends, dating, or going on vacations. He was embarrassed to ask his parents for financial support, but they offered to assist him, and his friends started an online crowdfunding campaign to defray costs.

Now, 2 years following completion of his cancer therapy, Jake continues to pay monthly costs for sperm storage. He sees his oncologist every 3 months to be monitored for recurrence and persistent or new-onset treatment-related complications. He has a new job with access to high-quality health insurance and paid time off. Jake recently met with a financial advisor to assess how he could resolve his debts and build his financial assets to regain his financial independence.

■ Discussion

This analysis provides conceptual clarity for financial toxicity by synthesizing literature from multiple disciplines, including nursing, medicine, economics, and social work. Using Rodger's evolutionary method of concept analysis,[16] we selected antecedents, attributes, and consequences (Figure 2) to show how financial toxicity is used across disciplines. Our findings highlight financial toxicity in AYA cancer survivors as more than out-of-pocket spending for cancer therapy, other cancer-related costs, or an AYA's financial health at diagnosis.[13,51] Further, conceptualizing financial toxicity solely based on financial burden failed to capture the experience of financial distress. We found inconsistency in the literature regarding use of financial toxicity and its related terms, financial burden, distress, stress, and hardship.[19]

Our results underscore the importance to identify the specific needs of AYA cancer survivors, including racial or ethnic minority group members, or AYAs who have lower socioeconomic status who may be at heightened risk of financial toxicity.[20,47,51]

Limitations

Limitations of this concept analysis are discussed below. While the first author performed the search and analysis alone, there was frequent communication among all coauthors on the findings of the analysis and development of Figure 2.

While the literature reviewed for this concept analysis was not limited by study location, the results may not capture differences in the antecedents, attributes, and consequences of financial toxicity for AYAs residing in the United States as compared with those residing other high-income countries. While taxpayer-funded health insurance and paid medical leave may mitigate financial toxicity, treatment-related out-of-pocket expenses and lost educational and employment-related opportunities during the AYA period are likely problematic in high-income countries beyond the United States.[53] As suggested by research and care of children with cancer, financial toxicity may be experienced differently by AYAs who reside in low- and middle-income countries that lack healthcare infrastructure and where cancer therapy may be delayed, abandoned, or never initiated for reasons that include a high prevalence of poverty in the population,[54] beliefs about incurability or misperceptions of cure when signs and symptoms abate,[55] inability to pay in cash prior to treatment initiation or release from hospital,[56] and/or gender-based biases that favor healthcare for males.[57] In addition, samples in the included studies lacked gender

and racial diversity; samples were predominantly White and female. Thus, differences in the conceptualization of some attributes of financial toxicity, such as financial burden, may differ by age, residence, and other sociodemographics within the AYA population.[6,35] In addition, this analysis does not capture literature prior to 2013 when the term *financial toxicity* was introduced; thus, literature describing what is now considered financial toxicity was not included (eg, see Keim-Malpass and Steeves[58] and Keim-Malpass et al[59]).

Themes related to financial toxicity were mostly derived from patient-reported outcomes and qualitative findings from AYA survivors. Studies did not evaluate others who might also experience financial toxicity, such as family and/or caregivers. The effects of AYA cancer on family members and other caregivers' financial well-being, household material hardship, and quality of life should be explored in future studies.

The case presented as an exemplar illustrates what contributes to financial toxicity, as well as what AYAs can do to mitigate it. As Rodgers and Knafl[16] note, exemplars for concepts that are in need of further development, such as financial toxicity in AYAs, should be considered with caution. The challenges for Jake represent a best-case scenario for an AYA in many ways. He is a college graduate, is employed at diagnosis with employer-sponsored health insurance, has accommodations at work, and has a supportive family and friends with monetary assets that they shared. In addition, he received financial assistance to pay for fertility preservation, which is a simpler and less costly process for males. Areas not presented in the exemplar (eg, AYAs with minimal financial support, non–employer-sponsored health insurance, or with recurrence and/or multiple treatment regimens) are in need of further development when studying financial toxicity in AYAs with cancer.

Further, while this search occurred during the COVID-19 pandemic, articles specific to the impact of COVID-19 on cancer and financial toxicity were not included. We acknowledge that these consequences may be an important consideration in future studies, especially considering the role of competing financial pressures in the development of financial toxicity.

Implications

This analysis lays the groundwork for development of a conceptual basis for future research of financial toxicity in AYA cancer survivors. Concept analysis is essential to understanding the components and boundaries of complex concepts, the development of valid means for measuring those concepts and examining hypothetical linkages to indicators of concepts in theory-based descriptive and interventional research. Our analysis highlights specific areas for the development and testing of interventions to mitigate financial toxicity in AYAs diagnosed with cancer. Given their roles in financial toxicity, we argue the components outlined in Figure 2 (antecedents, attributes, and consequences) be measured when assessing and intervening with AYAs.

Across oncology populations, financial toxicity research is moving toward designing and testing multilevel theory-based interventions to mitigate its adverse effects on care, financial, and quality-of-life outcomes. Santacroce and Kneipp[53] adapted a model for adult oncology to describe the preexisting risk and protective factors, sources of cancer-induced financial burden, financial distress, financial coping behaviors, and health and financial outcomes that encompass financial toxicity in the pediatric oncology context. Further, a recent commentary[60] proposed a theoretical model of financial burden after cancer diagnosis for all ages of cancer survivors, addressing the gaps in understanding constructs between financial burden and its moderators or causes.

Although financial toxicity may be an adverse effect for all cancer survivors regardless of age or stage of diagnosis, studies specific to AYAs are needed, particularly among racial or ethnic minorities and those with socioeconomically disadvantaged backgrounds.

Essential to intervention development and testing are reliable and valid population-specific measures of financial toxicity that can be used to determine efficacy. No standardized approach to measuring the multiple phenomena that comprise financial toxicity currently exists.[10] Two common tools in use are the Comprehensive Score for Financial Toxicity, which assesses financial toxicity in the adult oncology context,[43] and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, which assesses quality of life in the context of financial toxicity among adult oncology populations.[36] Although useful, these tools do not address all the multidimensional factors of financial toxicity[6] and have not been validated with AYA populations. (Of note, as of December 2020, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire is in phase 2 development for AYAs.)[21]

To identify when cancer-related financial burden so exceeds available financial resources as to cause "toxicity" and financial coping behaviors (eg, suboptimal adherence) that can be harmful in the long term, we need to identify modifiable components of financial toxicity.[3] Whereas Salsman et al[36] incorporate material conditions to financial burden, our analysis highlighted a gap in the literature on material hardship among AYAs with cancer. Data were limited to studies using grant applications specific for financial assistance after cancer treatment (eg, unable to pay rent or utilities).[14,31] Additional research is needed to determine the impact of material hardship (eg, not having enough food, not having transportation to medical care) on financial toxicity.[27]

More research is also needed to clarify how the attributes of financial burden and financial distress differ from poor financial well-being and psychological functioning as a consequence of financial toxicity. Carrera et al[40] include anxiety and discomfort as components of subjective financial distress (ie, attributes rather than consequences). The relationship between physical and psychological stress in regard to financial toxicity in AYAs with cancer has yet to be adequately explored, and this may be a contributor to the consequence of poor care outcomes, which may include shorter time to recurrence, and excess morbidity and mortality compared with others with similar biological risk factors. We lack evidence for whether, and if so how, chronic stress in AYAs with cancer contributes to their already heightened risk of secondary chronic conditions due to cancer therapies received.[29]

While research of financial toxicity to date has focused on cancer populations, it seems logical that other chronic illness populations are also at risk, including patients in the AYA age group. Future research can apply our analysis of financial toxicity in AYA cancer survivors to AYAs with other chronic illnesses,

although careful consideration should be made in relation to costs of care, treatment duration, and risk of treatment-related comorbid conditions.

The use of Rodgers' evolutionary method[16] allows for flexibility with the ever-changing social and political climate, as financial toxicity will likely evolve dynamically along with healthcare costs and policies.[16] For example, policy changes to student loan repayment in the future may impact the competing financial pressures faced by AYAs. A gap also exists in the literature examining work-related components of financial toxicity; the majority (60%) of studies, in a 2016 systematic review of financial hardship in cancer,[19] did not include a work-related measure of financial toxicity (eg, lost productivity measured by inability to work).[34] Large portions of the AYA population work in service sector jobs for low hourly wages and no benefits and thus are at risk of loss of income from cancer-related work disruptions, a known driver of financial toxicity.[46] Using the findings from our concept analysis, future research should specifically examine reduction in income among AYAs who are hourly wage earners, given their higher risk of employment loss and other cancer-related work disruptions.[40]

Findings outlined in Figure 2 may be used to explore the impact of the COVID-19 pandemic on financial toxicity in AYAs with cancer. Unemployment driven by this pandemic may worsen precancer financial status for AYAs overall and contribute to attributes and consequences such as financial dependence on parents, foregoing independent living, and/or delaying pursuit of higher education. Future research should also explore the lessons learned about working from home during the pandemic and how similar accommodations might benefit vulnerable AYAs with cancer or another chronic illness beyond the pandemic.

Increased focus on financial toxicity is being applied in adult oncology practice, such as drawing attention to medical costs and using a patient-centered practice approach. Thought leaders such as Zafar et al[61] advocate for considering prognosis when discussing care goals as part of treatment decision making and the financial implications of those decisions. Specifically, AYAs with cancer and their providers should have conversations about the cost of their cancer treatment and surveillance and the demands these costs place on their finances. Conversations about costs and finances can be embarrassing for AYAs with cancer and their providers,[35] which raises concerns about being offered less costly care, which they equate with receiving less effective, therapies if they reveal financial concerns. All members of the healthcare team, including oncology nurses, should understand the attributes and consequences of financial toxicity for AYAs throughout the cancer trajectory and further encourage AYAs to be active participants in their care by engaging in financial discussions with the institution's financial navigators. In addition, social workers can comprehensively assess their financial needs and provide a referral to resources within and outside the healthcare setting.

■ Conclusion

Financial toxicity in AYAs with cancer includes financial burden and financial distress amid the financial pressures during adolescence and young adulthood. Its global consequences in AYAs with cancer are profound and will continue to evolve over time with changes in health systems and the economy. Through concept analysis, we found several implications for future research, with some extending to AYA populations beyond oncology, to reduce financial toxicity and its adverse and persistent consequences.

References

1. National Cancer Institute. Adolescents and young adults (AYAs) with cancer. National Institutes of Health. Published 2018. https://www.cancer.gov/types/aya. Accessed September 17, 2018.
2. Institute of Medicine of the National Academies. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: The National Academies Press; 2005.
3. Lentz R, Benson AB, Kircher S. Financial toxicity in cancer care: prevalence, causes, consequences, and reduction strategies [published online January 16, 2019]. *J Surg Oncol*. 2019;120(1):85–92. doi:10.1002/jso.25374.
4. Ratain M. *Biomarkers and Clinical Care. Personalized Medicine in an Era of Health Care Reform. Presented at the: AAASFDLI Colloquium*; October 26, 2009. Washington, DC; 2009.
5. Zafar SY, Abernethy AP. Financial toxicity, part I: a new name for a growing problem. *Oncology (Williston Park)*. 2013;27(2):80–81, 149.
6. Kaul S, Kirchhoff AC. Closing the financial toxicity gap for adolescents and young adults with cancer. *Pediatr Blood Cancer*. 2019;66(7):e27742.
7. Zafar SY. Financial toxicity of cancer care: it's time to intervene. *J Natl Cancer Inst*. 2016;108(5):djv370.
8. Gordon LG, Chan RJ. Financial toxicity among patients with cancer—where to from here? *Cancer Nurs*. 2017;40(4):257–258.
9. Witte J, Mehlis K, Surmann B, et al. Methods for measuring financial toxicity after cancer diagnosis and treatment: a systematic review and its implications. *Ann Oncol*. 2019;30(7):1061–1070.
10. Thomas T, Hughes T, Mady L, Belcher S. Financial toxicity: a review of the literature and nursing opportunities. *Clin J Oncol Nurs*. 2019;23(5):5–13.
11. Desai A, Gyawali B. Financial toxicity of cancer treatment: moving the discussion from acknowledgement of the problem to identifying solutions. *EClinicalMedicine*. 2020;20:100269.
12. Semler R, Thom B. Fertility preservation: improving access through nurse-advocated financial assistance. *Clin J Oncol Nurs*. 2019;23(5):27–30.
13. Kaddas HK, Pannier ST, Mann K, et al. Age-related differences in financial toxicity and unmet resource needs among adolescent and young adult cancer patients. *J Adolesc Young Adult Oncol*. 2020;9(1):105–110.
14. Macpherson CF, Johnson RH, Landwehr MS, Watson SE, Stegenga K. "Aftermath": financial resource requirements of young adults moving forward after cancer treatment [published online December 17, 2019]. *J Adolesc Young Adult Oncol*. 2020;9(3):354–358. doi:10.1089/jayao.2019.0120.
15. Hupcey JE, Penrod J. Concept analysis: examining the state of the science. *Res Theory Nurs Pract*. 2005;19(2):197–208.
16. Rodgers BL, Knafl KA. *Concept Development in Nursing: Foundations, Techniques, and Applications*. Philadelphia, PA: Saunders; 2000.
17. Tofthagen R, Fagerstrøm LM. Rodgers' evolutionary concept analysis—a valid method for developing knowledge in nursing science. *Scand J Caring Sci*. 2010;24(suppl 1):21–31.
18. Polit DF, Beck CT. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. Philadelphia, PA: 10th North American ed. Lippincott Williams & Wilkins; 2016.
19. Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR. Financial hardships experienced by cancer survivors: a systematic review. *J Natl Cancer Inst*. 2016;109(2):djw205.
20. Ashing KT, George M, Jones V. Health-related quality of life and care satisfaction outcomes: Informing psychosocial oncology care among Latina and African-American young breast cancer survivors. *Psychooncology*. 2018;27(4):1213–1220.

21. Banegas MP, Guy GP, de Moor JS, et al. For Working-Age Cancer Survivors, Medical Debt And Bankruptcy Create Financial Hardships. *Health Aff (Millwood)*. 2016;35(1):54–61. doi:10.1377/hlthaff.2015.0830.
22. Benedict C, McLeggon JA, Thom B, et al. "Creating a family after battling cancer is exhausting and maddening": exploring real-world experiences of young adult cancer survivors seeking financial assistance for family building after treatment. *Psychooncology*. 2018;27(12):2829–2839.
23. Fidler MM, Frobisher C, Hawkins MM, Nathan PC. Challenges and opportunities in the care of survivors of adolescent and young adult cancers. *Pediatr Blood Cancer*. 2019;66(6):e27668.
24. Gordon LG, Merollini KMD, Lowe A, Chan RJ. A systematic review of financial toxicity among cancer survivors: we can't pay the co-pay. *Patient*. 2017;10(3):295–309.
25. Gupta SK, Mazza MC, Hoyt MA, Revenson TA. The experience of financial stress among emerging adult cancer survivors [published online January 25, 2020]. *J Psychosoc Oncol*. 2020;38(4):435–448. doi: 10.1080/07347332.2019.1707928.
26. Guy GP Jr., Yabroff KR, Ekwueme DU, et al. Estimating the health and economic burden of cancer among those diagnosed as adolescents and young adults. *Health Aff (Millwood)*. 2014;33(6):1024–1031.
27. Meernik C, Kirchhoff AC, Anderson C, et al. Material and psychological financial hardship related to employment disruption among female adolescent and young adult cancer survivors. *Cancer*. 2020;127(1): 137–148. doi:10.1002/cncr.33190.
28. Jones SMW, Yi JC, Jim HSL, et al. Age and gender differences in financial distress among hematopoietic cell transplant survivors [published online January 8, 2020]. *Support Care Cancer*. 2020;28(9):4361–4371. doi: 10.1007/s00520-019-05291-1.
29. Kaul S, Avila JC, Mehta HB, Rodriguez AM, Kuo Y-F, Kirchhoff AC. Cost-related medication nonadherence among adolescent and young adult cancer survivors. *Cancer*. 2017;123(14):2726–2734. doi:10.1002/cncr.30648.
30. Ketterl TG, Syrjala KL, Casillas J, et al. Lasting effects of cancer and its treatment on employment and finances in adolescent and young adult cancer survivors. *Cancer*. 2019;125(11):1908–1917.
31. Landwehr MS, Watson SE, Macpherson CF, Novak KA, Johnson RH. The cost of cancer: a retrospective analysis of the financial impact of cancer on young adults. *Cancer Med*. 2016;5(5):863–870.
32. Mcneil R, Mccarthy M, Dunt D, et al. Financial Challenges of Cancer for Adolescents and Young Adults and Their Parent Caregivers. *Social Work Research*. 2018;43. doi:10.1093/swr/svy027.
33. Murphy CC, Fullington HM, Alvarez CA, et al. Polypharmacy and patterns of prescription medication use among cancer survivors. *Cancer*. Published online July 2018. doi:10.1002/cncr.31389.
34. Pearce A, Tomalin B, Kaambwa B, et al. Financial toxicity is more than costs of care: the relationship between employment and financial toxicity in long-term cancer survivors. *J Cancer Surviv*. 2019;13(1):10–20.
35. Perez GK, Salsman JM, Fladeboe K, Kirchhoff AC, Park ER, Rosenberg AR. Taboo topics in adolescent and young adult oncology: strategies for managing challenging but important conversations central to adolescent and young adult cancer survivorship. *Am Soc Clin Oncol Educ Book*. 2020;40:1–15.
36. Salsman JM, Bingen K, Barr RD, Freyer DR. Understanding, measuring, and addressing the financial impact of cancer on adolescents and young adults [published online February 12, 2019]. *Pediatr Blood Cancer*. 2019;66(7):e27660.
37. Tan CJ, Ke Y, Ng T, et al. Work- and insurance-related issues among Asian adolescent and young-adult cancer survivors: a qualitative study. *Support Care Cancer*. Published online April 8, 2020. doi:10.1007/s00520-020-05430-z.
38. Thom B, Benedict C. The impact of financial toxicity on psychological well-being, coping self-efficacy, and cost-coping behaviors in young adults with cancer [published online February 28, 2019]. *J Adolesc Young Adult Oncol*. 2019;8(3):236–242. doi:10.1089/jayao.2018.0143.
39. Thom B, Benedict C, Friedman DN, Kelvin JF. The intersection of financial toxicity and family building in young adult cancer survivors. *Cancer*. 2018;124(16):3284–3289.
40. Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin*. 2018;68(2):153–165.
41. Chan RJ, Gordon LG, Tan CJ, et al. Relationships Between Financial Toxicity and Symptom Burden in Cancer Survivors: A Systematic Review. *Journal of Pain & Symptom Management*. 2019;57(3):646–646. doi:10.1016/j.jpainsymman.2018.12.003.
42. Chi M. The hidden cost of cancer: helping clients cope with financial toxicity. *Clinical Social Work Journal*. Published online October 11, 2017. doi:10.1007/s10615-017-0640-7.
43. de Souza JA, Yap BJ, Hlubocky FJ, et al. The development of a financial toxicity patient-reported outcome in cancer: the COST measure. *Cancer*. 2014;120(20):3245–3253.
44. Fessele KL. Financial Toxicity: management as an adverse effect of cancer treatment. Clinical Journal of Oncology Nursing. 2017;21(6):762–764. doi:10.1188/17.CJON.762-764.
45. Lathan CS, Cronin A, Tucker-Seeley R, Zafar SY, Ayanian JZ, Schrag D. Association of financial strain with symptom burden and quality of life for patients with lung or colorectal cancer. *JCO*. 2016;34(15):1732–1740. doi:10.1200/JCO.2015.63.2232.
46. Koczwara B. Unemployment after cancer—a hidden driver of financial toxicity [published online July 2017]. *Cancer Forum*. 2017;41(2): https://cancerforum.org.au/forum/2017/july/unemployment-after-cancer-a-hidden-driver-of-financial-toxicity/#10. Accessed December 29, 2020.
47. Smith AW, Keegan T, Hamilton A, et al. Understanding care and outcomes in adolescents and young adult with cancer: a review of the AYA HOPE study. *Pediatr Blood Cancer*. 2019;66(1):e27486.
48. Tran G, Zafar SY. Financial toxicity and implications for cancer care in the era of molecular and immune therapies. *Ann Transl Med*. 2018;6(9):166.
49. Stone DS, Ganz PA, Pavlish C, Robbins WA. Young adult cancer survivors and work: a systematic review. *J Cancer Surviv*. 2017;11(6):765–781.
50. Ramsey S, Blough D, Kirchhoff A, et al. Washington state cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)*. 2013;32(6):1143–1152.
51. National Cancer Institute (NCI). Financial toxicity (financial distress) and cancer treatment. Published 2018. https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq. Accessed December 29, 2020.
52. Kale HP, Carroll NV. Self-reported financial burden of cancer care and its effect on physical and mental health-related quality of life among US cancer survivors. *Cancer*. 2016;122(8):283–289.
53. Santacroce SJ, Kneipp SM. A conceptual model of financial toxicity in pediatric oncology. *J Pediatr Oncol Nurs*. 2019;36(1):6–16.
54. Friedrich P, Lam CG, Itriago E, Perez R, Ribeiro RC, Arora RS. Magnitude of treatment abandonment in childhood cancer. *PLoS One*. 2015;10(9):e0135230.
55. Alam A, Kumar A. Prevalence, predictors, causes of treatment refusal and abandonment in children with acute lymphoblastic leukaemia over 18 years in North India. Treatment phase affecting factors: a step towards better focussed counselling. *Cancer Epidemiol*. 2018;57:53–59.
56. Mostert S, Njuguna F, Langat SC, et al. Two overlooked contributors to abandonment of childhood cancer treatment in Kenya: parents' social network and experiences with hospital retention policies. *Psychooncology*. 2014;23(6):700–707.
57. Ganguly S, Kinsey S, Bakhshi S. Childhood cancer in India. *Cancer Epidemiol*. 2021;71:101679.
58. Keim-Malpass J, Steeves RH. Talking with death at a diner: young women's online narratives of cancer. *Oncol Nurs Forum*. 2012;39(4):373–378.
59. Keim-Malpass J, Baernholdt M, Erickson JM, Ropka ME, Schroen AT, Steeves RH. Blogging through cancer: young women's persistent problems shared online. *Cancer Nurs*. 2013;36(2):163–172.
60. Jones SM, Henrikson NB, Panattoni L, Syrjala KL, Shankaran V. A theoretical model of financial burden after cancer diagnosis. *Future Oncol*. 2020;16(36):3095–3105.
61. Zafar SY, Tulsky JA, Abernethy AP. It's time to have 'the talk': cost communication and patient-centered care. *Oncology (Williston Park)*. 2014;28(6):479–480.