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HEALTH ECONOMICS (N KHERA, SECTION EDITOR)

Financial Hardship—an Unwanted Consequence of Cancer Treatment

Julie McNulty [1] · **Nandita Khera** [2]

Abstract The substantial economic burden of cancer is increasingly being shifted to patients. Financial burden experienced by patients as a result of medical treatment has an impact on their lifestyle choices, health behaviors, and quality of life. Variation in treatment recommendations based on the patients' economic status or affordability may be against the basic tenet of social justice and is a growing challenge for policy makers. This review summarizes the multifaceted constructs and current trends associated with financial hardship within the context of cancer care and healthcare economics focusing mainly on hematological malignancies but supplemented by nonhematological cancer and general medical literature. We also highlight the patient and physician perspectives about this issue and identify important areas for future research. We discuss the need for more proactive solutions so that patients can achieve good clinical outcomes, without catastrophic financial consequences for themselves and their families.

Keywords Financial burden · Cancer · Leukemia · Lymphoma · Multiple myeloma · Financial toxicity

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✉ Julie McNulty
Julie.mcnulty@asu.edu

Nandita Khera
hera.nandita@mayo.edu

[1] 500 N 3rd St, Phoenix, AZ 85004, USA

[2] 5777 E Mayo Blvd, Phoenix, AZ 85054, USA

Introduction/Scope of the Problem

Financial hardship as a result of cancer diagnosis and treatment is a growing challenge for patients and healthcare providers and is being described as "financial toxicity" analogous to medical toxicity of these therapies [1]. While medical costs are a significant component of this burden, nonmedical costs such as lodging/travel to cancer centers or indirect costs from loss of employment and income for the patient and caregiver also contribute to it.

There is a lot of variation in prevalence rates of financial hardship in cancer studies ranging from 12 to 80 % due to use of different definitions, measures, and heterogeneity of cancer diagnosis and settings in which these studies have been conducted [2•, 3–5, 6•, 7]. The impact of financial burden on patients and families is described quite well by multiple investigators, but it may have broader system level consequences due to its impact on quality of care, health care utilization, and potential worsening of health care disparities.

The purpose of this review is to explore the multifaceted constructs and current trends associated with financial hardship within the context of cancer care and healthcare economics. We also include examples from nononcology literature to provide a better understanding of some issues in this area such as barriers in communication between physicians and patients about costs of care. Implications for research and practice including potential solutions to address this problem will also be discussed.

Methods

Search Strategy The MEDLINE database was searched using the following terms: "cancer" or "leukemia" or "myeloma" or "lymphoma" and "economic burden" or "financial burden" or "financial distress" or "financial hardship" or "out-of-pocket spending/costs" or "financial" or "employment." Studies focusing on financial burden in pediatric cancers were not included. Only articles published in English between January 1, 1986, and December 31, 2014, were considered. The reference lists from publications were reviewed to identify other relevant papers. Abstracts were reviewed and full-text articles were retrieved if the study reported any information about financial burden as a primary or secondary outcome. Each study was summarized by J.M. with secondary review by N.K.

What Is Financial Toxicity and How Do We Measure It?

Financial toxicity may be defined as adverse economic consequences due to medical treatment that can result in treatment nonadherence and lifestyle changes for patients that have an impact on their quality of life and increase the morbidity and mortality of treatments. The main categories of expenses incurred by patients and families are medical costs, nonmedical costs such as travel and housing, and indirect costs due to lost wages for the patient and caregiver. Medical costs due to cost-sharing (deductibles, copayments, prescription and nonprescription medications and payments for services that are not covered by health insurance) have been described in majority of the studies [8–10]. Table 1 summarizes some of the studies describing financial burden in patients with malignancies.

While premiums are not usually considered a part of the out of pocket (OOP) expenditure, they have an impact on the affordability of insurance which, in turn, is very intricately related to financial burden experienced by patients. Young and DeVoe have estimated that the employee contribution to a family premium plus OOP costs will comprise one half the household income by 2031 and total income by 2042 leaving no money for other necessities, if the current trends in health care expenditure continue [18]. Indirect costs are harder to estimate. Recently, investigators used data from 2008 to 2010 Medical Expenditure Panel Survey (MEPS) Household Component to report that the total annual per capita lost productivity was $4694 among recently diagnosed cancer survivors, as compared to $2040 among individuals without a history of cancer [19]. This still is an underestimate since it does not include caregivers' productivity loss.

Measures for financial toxicity are underdeveloped, and there is heterogeneity of instruments described in the literature. In a recent review, Azzani and colleagues found that some studies used categorical measures, while others used Likert rating scales of agreement [20•]. Proxy indicators such as debt accrued or sale of assets to pay medical bills have also been used by some researchers. Most investigators utilized self-developed questionnaires in order to capture information about financial concerns and sociodemographic factors such as household income, employment status, and health insurance that may impact them [3–5, 12].

Head and Faul developed the socioeconomic well-being scale which includes subscales measuring human, material, and social capital, and showed acceptable reliability, content, and construct validity at both scale and item levels [21]. Recently, de Souza and colleagues reported on the initial development of a patient reported outcomes measure, the COST, an 11-item instrument to assess the degree of financial distress experienced by the participants. The COST measure demonstrated content and face validity as well as internal consistency. Further psychometric work is needed on this instrument and it needs to be tested across a spectrum of hematological malignancies since the original study sample had underrepresentation from hematological cancers [22].

Who Is at Risk and What Are the Predictors?

Various sociodemographic and clinical factors have emerged as important predictors for financial toxicity in studies that have described the financial impact of cancer treatment. Younger patients may have more difficulty facing financial adjustments in the face of cancer costs because of higher baseline household expenses related to mortgage payments or child-rearing and few years over which to accumulate assets [3–5, 6•]. On the other hand, older individuals with multiple medical problems may face higher OOP cost burden due to need for more services, but some of it may be buffered because of Medicare [23]. However, having Medicare by itself may not be enough as was reported by Davidoff et al. who found that OOP spending and the burden of OOP spending relative to income is substantially higher in Medicare beneficiaries with newly diagnosed cancer compared with beneficiaries without cancer [24]. Not surprisingly, having a higher household income and being employed decrease the likelihood of experiencing financial hardship [3–5]. In addition, patients from racial/ethnic minorities or from rural areas have been traditionally considered as financially disadvantaged and may have a higher burden of cancer-related financial problems [5, 6•, 25].

Very few disease-related factors such as recurrent cancer or shorter time since diagnosis have been found to be significantly associated with financial burden experienced by patients especially when evaluated in the context of sociodemographic factors as described above [6•]. The spiraling costs of new therapeutic agents are a well-recognized problem, for example, in Chronic Myeloid Leukemia (CML), three new drugs that were recently approved include ponatinib at $138,000 per year, omacetaxine at $28,000 for induction and $14,000 per maintenance course, and bosutinib at about $118,000 per year [26]. Because of the cost-sharing aspect with most health care

Table 1 Summary of studies in hematological and solid malignancies evaluating financial burden of treatment

Study/year	Study type	Diagnosis/sample size	Major findings
Meneses-2011 [11]	Regional centers, wait control arm of interventional study	Breast N=132	Increase in economic events was associated with poorer QOL at baseline and follow up
Kodama-2012 [7]	Multicenter cross-sectional survey based	CML receiving imatinib N=577	Higher likelihood of discontinuation of imatinib if higher cost-sharing
Goodwin-2013 [12]	Single center, descriptive/cross sectional survey based	Multiple myeloma N=762	Employment, disability, insurance and out-of-pocket costs are major challenges 36 % of income spent on treatment related expenses during the first 12 months of treatment
Shakaran-2012 [3]	Population based, cross-sectional	Colon N=284	Younger age, lower income, and unemployment or disability most closely associated with treatment nonadherence
Hamilton 2013 [13•]	Multicenter, cross-sectional	HCT recipients N=181	Financial stress associated with poor HRQOL
Kent 2013 [6•]	Population based (NHIS)	Mixed N=1556 (overall); 99 (hematological cancer)	32 % reported cancer-related financial problems making patients more likely to forgo or delay their medical care
Majhail 2013 [9]	Multicenter surveys, diaries, and interviews	HCT recipients and caregivers N=30	Substantial out-of-pocket costs over the first 3 months after HCT Relocation adds to financial burden for HCT patients
Chino 2014 [14]	National sample, observational/cross-sectional (private foundation providing financial assistance)	Breast/mixed (all solid tumor) N=174	Financial burden is a potentially modifiable correlate of poor satisfaction with cancer care
Jagsi 2014 [5]	Descriptive-longitudinal (SEER data)	Breast N=1502	Minorities are most vulnerable to financial decline
Khera 2014 [15]	Multicenter, cross-sectional	Allogeneic HCT recipients N=268	47 % of respondents experienced financial burden Younger age and poor mental and physical functioning increased the likelihood of financial burden
Fenn 2014 [16]	Descriptive/correlational (NHIS data)	Mixed N=2108	Thyroid, ovarian, and lung cancer patients reported the highest level of financial burden. Increased financial burden was the strongest predictor of QOL
Dusetzina 2014 [17•]	Population based (health plan claims)	CML N=1541	Patients with higher copayments are more likely to discontinue or be nonadherent to TKIs
Zafar 2014 [2•]	Health system, surveys, baseline, and follow-up	Solid tumor/mixed N=254	Younger age, larger household size, applying for co-payment assistance, and communicating with physician about costs associated with greater financial burden

CML chronic myeloid leukemia, *HRQOL* health-related quality of life, *HCT* hematopoietic cell transplantation, *SNHIS* National Health Interview Survey, *SEER* Surveillance, Epidemiology, and End Results Program, *TKIs* tyrosine kinase inhibitors

insurances (20 % copayment is typical), even the insured patients may face considerable financial burden for such treatments. A similar situation is seen with use of high-cost medical technologies such as hematopoietic cell transplantation (HCT), commonly used for various hematologic disorders where despite high rates of insurance, 47 % patients reported objective financial burden [4].

What Are the Consequences of Financial Toxicity?

Dr. Schilsky, American Society of Clinical Oncology (ASCO) leader, recently commented: “Our goal as doctors is to provide our patients with the best medicine possible based on the best science available, but the cost of care is starting to creep into the exam room and affect the treatment decisions we make with our patients.”

There is no doubt that financial burden of cancer treatments will have far-reaching consequences not only on the patients but also on health care system and quality of care in general. Impact of financial hardship on patients varies from lifestyle changes such as cutting back on leisure activities, reduced spending on utilities/food to borrowing money from friends/relatives or mortgaging/selling homes/assets [3, 4, 12]. In the general cancer population, the risk for bankruptcy has been reported to be 2.1 % at a median time of 2.5 years after diagnosis of cancer [27]. These effects may translate into poor psychosocial outcomes for patients experiencing financial burden with higher stress, decreased quality of life, and greater incidence of depression and anxiety as well as increased uncertainty during the recovery process [9, 11, 13•, 16, 28].

Another important consequence of financial burden is the spectrum of potentially deleterious health behaviors that occur as a result of concern about costs of care. This ranges from forgoing overall medical care, switching from more expensive though more effective therapy to less costly though less effective alternative or not using ancillary services [3, 4, 6•, 29]. Higher copayment was associated with a higher rate of nonadherence or discontinuation of tyrosine kinase inhibitors in patients with CML which undoubtedly puts them at risk for relapsed disease and treatment resistance [17•]. Other characteristics that are significantly associated with economically motivated treatment adherence include younger age, lower income, unemployment or disability, lower educational attainment, and racial/ethnic minorities [3, 4, 29].

While there is lack of data in hematology/oncology of whether financial burden has a direct impact on clinical outcomes, there is a recent study that showed that economic insecurity in patients was associated with poor diabetes control as well as increased use of health care resources [30]. An ongoing multicenter study is exploring the association of clinical outcomes 1 year after an autologous or allogeneic HCT with financial hardship assessed at 6 months after HCT [31].

Because of increased burden of OOP costs which may influence the decision making even though not explicitly, disparities in cancer care may become more glaring [32]. Physicians are less likely to refer leukemia patients for a transplant consult if the patient does not have insurance [33]. Rising costs of cancer therapies have the potential to create "economic disparity" in access to treatment and worsen the disparities due to race/ethnicity with minority patients bearing the brunt of poor quality/suboptimal care due to cost pressures. Figure 1 summarizes the risk factors for and consequences of financial toxicity.

What Is the Physician and Patient Perspective About Financial Toxicity?

Very few studies have assessed the attitudes and practices of oncologists and patient preferences about communication of OOP costs. Schrag et al. reported the variation in the attitudes and behaviors of practicing oncologists as elicited through a national level survey [34]. Interestingly, a vast majority of oncologists felt that the economic and not just the clinical consequences of treatment were important and should be explicitly discussed with the patient. However, only about 50 % of them actually did it. The other end of this spectrum was evaluated by researchers at Beth Israel in Boston who assessed the patient perspective on OOP costs [35•]. They found that a majority of the patients wanted to know and discuss about the cost-sharing aspect of their treatment, but they did not want it to influence decision-making.

The barriers in communication cited by both these studies are quite similar to those described by Alexander et al. [36] from general medicine literature and include discomfort with discussion about costs, lack of knowledge about economic consequences of treatment, and not being ready to take the responsibility for controlling costs on the part of the physicians. For the patient, the main challenges include misunderstanding the overall prognosis and efficacy of treatment, fear that they will not receive the most effective therapies if they show concern about financial concerns and perception that the physician may not be able to help address their problem. Unlike other medical problems, the life-threatening diagnosis of cancer brings on extreme physical, social, and emotional suffering. Therefore, the concern of finances usually becomes secondary to the primary objective of fighting the cancer at least at the time of diagnosis of cancer. This was well described by one of the post-transplant patients in the study by Kim et al.: "I believe everything was explained thoroughly and explicitly. But I don't think that when you face a last option to be able to live that you process it. You hear, understand and acknowledge it but only when you are on the other side of transplant you allow your mind and heart to process that it basically cost everything you own. When hope reappears, you process it because then you have a value to balance it against" [37].

What Strategies Can Be Used to Address This Problem?

Including cost of cancer care in patient-physician discussions early in the decision-making process is the first and foremost step that can help in ameliorating the financial toxicity. Variation in treatment recommendations based on the patients' economic status or affordability may be against the basic tenet of social justice and would be considered as rationing by some people. Alexander et al. have highlighted this problem quite well and suggested some ways to address it [38]. Discussion about the potential financial toxicity of treatment options would require the physician to be able to assimilate the available evidence in terms of clinical effectiveness, toxicities, and relative costs of various treatments to assist medical decision-making. We have previously raised the question if a standardized scoring system, similar to Common Terminology Criteria for Adverse Events (CTCAE), could be developed to assess and record the financial impact of illness and treatment [15]. Some other strategies that have been suggested to introduce this topic in discussion between the physicians and patients are to screen for financial harm and provide full disclosure of

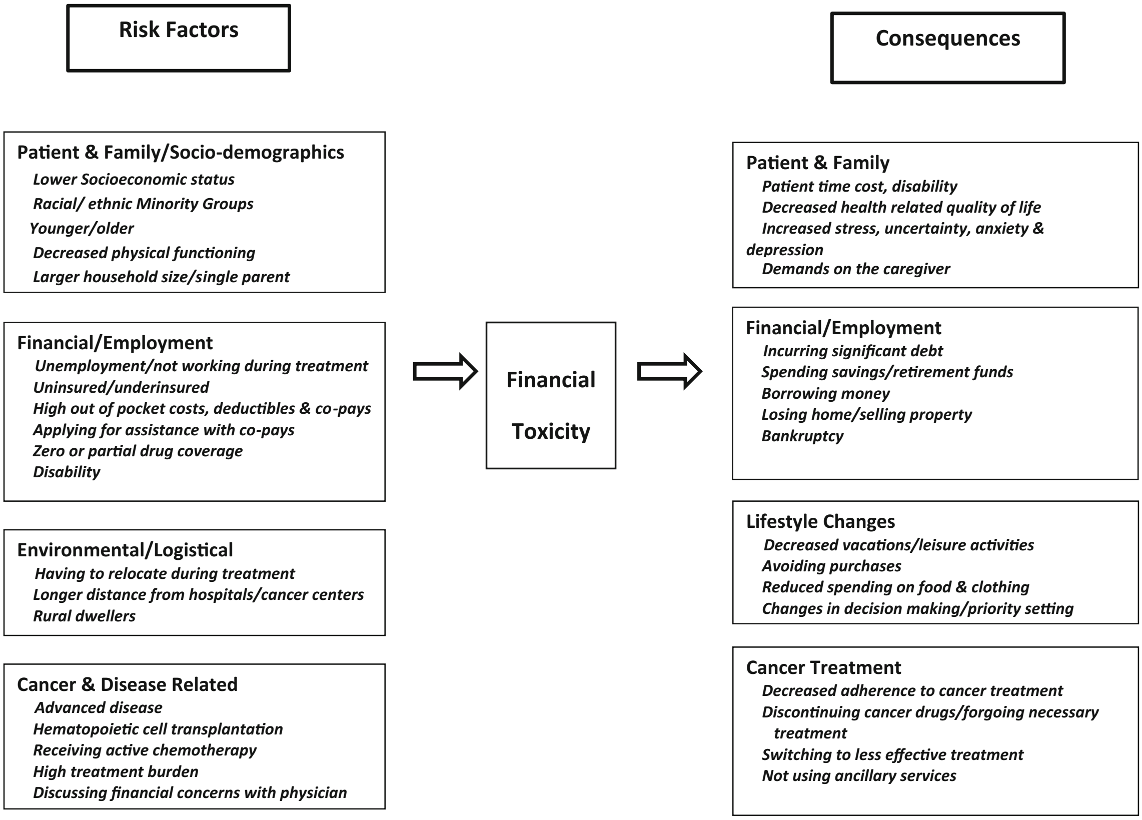

Fig. 1 Risks factors and consequences of financial toxicity in cancer patients and their families

financial considerations when discussing benefits and risks of different treatments [39, 40]. There is no doubt that, to achieve these objectives, there needs to be a change in the curricula of medical school, residency, and fellowship programs. Medical training needs to encompass teaching about consideration of societal as well as individual resources when recommending treatments with marginal efficacy but high costs and promote financial stewardship.

While increasing physicians' awareness about these issues, including costs of care in decision making and developing well-validated, easy to use screening tools to help identify vulnerable patients is important, it has to be followed up with increased efforts to connect patients with potential resources specific and individualized to their financial needs. Social workers and financial care counselors interact with patients in financial need and are instrumental in enhancing the delivery of financial resources to patients. In a recent qualitative study, Smith et al. reported that this group faces its own challenges in terms of resource limitations (e.g., stringent eligibility criteria, decreasing funds), barriers to access (e.g., limited social worker pool, patient reluctance to discuss financial distress with their health care team), and process inefficiencies. There is an ever widening chasm between supply and demand both in terms of personnel and real-time resources to help patients with cancer-related financial needs which needs to be addressed by policy changes at institutional as well as federal levels. Increasing partnerships between nonprofit programs/pharmaceutical companies/cancer societies can help enrich the pool of financial assistance resources to help at-risk patients continue optimal treatment without having to experience catastrophic financial consequences.

Another important step to help address this patient centric problem is developing resources to help educate patients about direct and indirect costs of their care. Patients need to have a better understanding of the clinical and economic consequences of the therapies proposed to help guide their decision making regarding treatment options. A recent study evaluating for the preparedness of Americans for Affordable Care Act demonstrated the lack of knowledge about basics of insurance such as inability to describe a deductible [41]. This observation is supported by Kim et al. who reported navigating the system and lack of knowledge about employment or insurance policies as a challenge toward better financial health after allogeneic HCT [37]. Use of decision aids, patient navigation resources, and improving financial literacy can greatly help decrease the financial distress arising from cancer treatment and help patients plan better. Involvement of patient advocacy organizations in these efforts is essential for the success of this approach.

What Is the Impact of Affordable Care Act on This Problem?

A recent report evaluated the impact of Affordable Care Act's subsidized insurance options and consumer protections on national trends in health care coverage and affordability and identified several overall positive trends including decline in the number of people who report cost-related access problems and medical-related financial difficulties [42].

Especially for the cancer patient population, the Affordable Care Act has some provisions that may be beneficial. Elimination of life time caps, limiting OOP expenditure, and prohibition of insurance companies to deny insurance on the basis of preexisting conditions/provision of universal health coverage may help decrease cost burden for patients with cancer at all stages of cancer treatment. However, there are limitations such as expansion of high deductible health plans, which may actually increase the financial toxicity [43]. Several states have adopted cost-sharing plans for low-income adults, which may also add to the financial burden [44]. Additionally, if an insurance plan purchased through a health care exchange does not cover care at a major cancer center, the patient may be faced with high out-of-pocket costs which will not be a part of the annual limitation on cost-sharing.

What Are the Implications for Research and Clinical Practice?

While financial toxicity of cancer care has emerged as an important area of research recently, there are gaps in the literature where more studies are needed such as

1. Standardization of how financial toxicity is measured
2. Characterization of the magnitude and impact of financial burden on decision making, health behaviors, and health outcomes
3. Assessment of impact of increased communication on patient satisfaction, health care utilization, and outcomes
4. Development of interventions to decrease financial burden without compromising quality and efficacy of care
5. Increasing studies with underserved populations since they may include a majority of the patients vulnerable for financial toxicity

There is no doubt that the increasing cost of health care translates into an ever increasing burden on the health care system and for individual patients. The importance of perspective on value in the case of cancer is unique. Unrealistic optimistic expectations regarding prognosis and response to therapy can distort the value of the recommended treatment for a patient whose main focus is to fight the cancer. A scientific way to approach this is the assessment of cost effectiveness, the formal approach to estimating value for money which is adopted by some European countries including National Institute for Health and Clinical Excellence (NICE) in England. Though this approach comes with the cost of greater restrictions and slower time to coverage, it is a reasonable strategy to address the rationing that arises due to cost-sharing. Malin, in an editorial, summed the ethical dilemma as "do we use science to help us reach consensus on what we are willing to pay for new therapies and innovation, or do we leave individual patients to wrestle with the skyrocketing costs of cancer care and treatment determined by their ability to pay?" [45]

Conclusions

Patients, hematologists/oncologists, and health systems face an increasingly dire situation, where costs are rising to keep pace with innovations. With the shift of these costs to patients, there is a looming threat that the benefits of new discoveries may get restricted to only the few who can afford them. It is paramount that we work towards bending the cost curve especially for the patient without compromising quality and efficacy of care so that they can experience good clinical outcomes but not at the expense of catastrophic financial outcomes for themselves or their family.

Compliance with Ethics Guidelines

Conflict of Interest Julie McNulty declares no potential conflicts of interest.

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