

Development of a Financial Literacy Course for Patients With Newly Diagnosed Cancer

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The term “financial toxicity” has gained traction in the oncology community in recent years and captures the spectrum of financial hardships faced by cancer survivors (eg, loss of productivity, high out-of-pocket [OOP] spending, depletion of savings, medical debt, bankruptcy). Recent evidence suggests that patients who experience financial toxicity are at risk for decreased treatment adherence, poorer quality of life, and worse survival.¹⁻⁴ The growing intersection between the financial and clinical aspects of cancer care thus represents an emerging challenge in oncology.

Despite an improved understanding of the problem of financial toxicity, there is a relative lack of research and guidance on how best to help families deal with the cost of cancer care. Organizations, such as the American Society of Clinical Oncology (ASCO), have called for increased communication between patients and oncologists about the cost of cancer care.^{5,6} We agree, but also believe that addressing this problem will require a comprehensive and multifaceted approach that targets various factors that contribute to financial toxicity: lack of awareness about how to navigate the costs of care, lack of budget planning, high OOP spending on cancer therapy, and difficulty in managing other fixed expenses (Figure). We propose that aligning patients with organizations and resources to help navigate the cost of their care may help to decrease and prevent their financial stress and burden.

In partnership with the nonprofit organization Consumer Education and Training Services (CENTS), which specializes in financial literacy and education for various groups throughout western Washington state, we are developing a financial literacy course targeted to patients with cancer. We intend for this course to provide not only basic information about health insurance, disability, and employment benefits, but also to provide 1-on-1 budget planning with a trained specialist. Because stakeholder input is important in the development of meaningful interventions, we conducted a qualitative survey-based study with the goal of obtaining feedback from patients regarding their financial experiences during treatment, interest level in a financial literacy

ABSTRACT

OBJECTIVES: Although patients with cancer often face serious financial hardships, few studies have reported on strategies to mitigate this burden. Improving literacy about the financial aspects of cancer care may decrease the negative financial impact of cancer diagnosis and treatment. We obtained input from patient stakeholders on the perceived value and optimal design of a financial literacy program in the advanced cancer setting.

STUDY DESIGN: Prospective cohort survey.

Methods: A series of semi-structured interviews were conducted, during which patients with either colorectal or breast cancer were asked to describe the impact of cancer on their finances and employment, to state their preferences about discussing costs with their providers, and to give input on development of a financial literacy course.

RESULTS: Twenty-one patients (76% Caucasian) completed interviews, the majority of whom had Medicare or commercial insurance (71%). Lost income from early retirement or disability was the most financially burdensome experience for 67% of patients. The majority of patients (76%) reported that a financial literacy course would be helpful in navigating the cost of cancer care. Most preferred the course be administered at diagnosis in a live group format.

CONCLUSIONS: Feedback from patients with cancer supported the development of a group financial literacy course that addresses barriers to discussing cost concerns, employment changes during cancer, and available resources for financial assistance.

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course, desired course content, and perspectives on communicating about costs with their providers.

METHODS

We conducted semi-structured, in-person interviews with patients with advanced cancer being treated at 2 University of Washington clinical sites (Harborview Medical Center [HMC] and Seattle Cancer Care Alliance [SCCA], both in Seattle). HMC is a county hospital with a large immigrant and uninsured population. SCCA is the outpatient clinical oncology arm of the University of Washington. The study protocol was approved by the institutional review boards at these institutions.

Patient Population

We identified patients 18 years or older with either metastatic breast cancer or colorectal cancer on active treatment at either HMC or SCCA. These cancers were chosen as they are both common diseases with many expensive treatment options.

Patient Interviews

The interview guide was developed in collaboration with CENTS, adopting many questions previously tested and used in a study assessing the financial experiences of patients with colon cancer.⁷ In order to maximize patient comfort and encourage feedback, an experienced nonclinical interviewer conducted all in-person interviews, transcribed them, and kept detailed field notes. Demographic and clinical information was obtained from review of the patients' electronic health records. Participants received a \$20 gift card incentive for their participation in the interview.

Data Analysis

This was a qualitative study using descriptive statistics to understand characteristics of the study population. Means, medians, and proportions were used to describe the types of financial challenges patients faced, levels of pre- and postdiagnosis financial stress, barriers to communication with providers, preference for a financial literacy course, and desired course structure and content. To identify the major topics that would inform a financial literacy course, the principal investi-

TAKEAWAY POINTS

We explored attitudes around the development of a financial literacy program for patients with cancer.

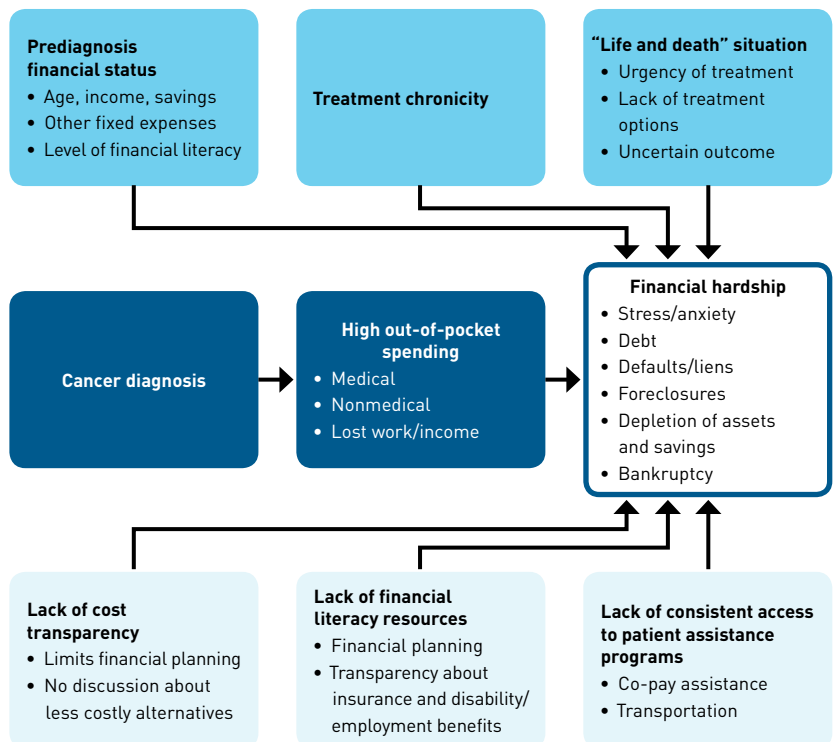
- ▶ Lost income from early retirement or disability was the most financially burdensome experience for 67% of patients with breast or colon cancer in our study.
- ▶ Over 75% of patients reported that a financial literacy course would be helpful in navigating the cost of cancer care.
- ▶ Major topics to cover in the financial literacy course include employment issues, barriers to discussing costs, and resources for financial assistance.

gator (author VS) actively reviewed and re-reviewed all transcripts and field notes in detail and identified recurring key themes by counting the frequencies of various constructs. Through iterative reading, provocative quotations and illustrative examples were established. Investigators then discussed the interview results with the CENTS project volunteers to inform the financial literacy course development.

RESULTS

A total of 21 patients across both institutions (HMC and SCCA) met eligibility criteria and completed in-person interviews. The majority of participants (mean age = 56 years) were women with breast cancer (76%) and were either commercially insured or had

FIGURE. Patient and Health System–Related Contributors to Financial Hardship



CASE STUDY

TABLE 1. Participant Characteristics

Patient Characteristics	Participants (n = 21)
Age, years	56 (mean)
Months after diagnosis	32 (median)
Diagnosis	
Breast cancer	16 (76%)
Colon cancer	5 (24%)
Clinic	
SCCA	16 (76%)
HMC	5 (24%)
Current treatment	
Hormonal	5 (24%)
Chemotherapy	14 (66%)
Observation	2 (10%)
Insurance	
Commercial	7 (33%)
Medicare	1 (5%)
Medicare + supplement	7 (33%)
Medicaid	4 (19%)
Charity	2 (10%)
Race	
White	16 (76%)
Black	2 (10%)
Asian	2 (10%)
Other	1 (5%)
Education	
<High school	1 (5%)
High school or GED	0 (0%)
Some college	10 (48%)
Bachelor's degree	6 (28%)
Master's degree	4 (19%)
Marital status	
Married	12 (57%)
Divorced/separated	4 (19%)
Widowed	1 (5%)
Never married	4 (19%)

GED indicates General Educational Development Test; HMC, Harborview Medical Center; SCCA, Seattle Cancer Care Alliance.

Medicare with a supplement plan (66%) (Table 1). Most patients were also highly educated and married (57%).

Knowledge and Resource Gaps Identified Through Patient Interviews

Key topics that were identified as important to address in developing the financial literacy course include: 1) implications of cancer on employment and income, 2) challenges in navigating and

understanding health insurance plans and bills, and 3) barriers and fears about discussing costs with healthcare providers.

Implications of Cancer Diagnosis on Employment and Income

The majority of patients in this study were employed prior to diagnosis (86%) and transitioned to unemployment, retirement, or disability as a result of cancer diagnosis (Table 2). A significant proportion of patients (67%) reported lost income as one of the most burdensome financial aspects of treatment relative to other aspects (eg, costs associated with chemotherapy, diagnostics, transportation). Although there was some evidence of poor financial health in patients before diagnosis (19%), approximately 75% of all patients experienced a major financial hardship—including accrual of debt and nonadherence to cancer treatment due to cost concerns—following diagnosis as a result of cancer-related spending. The proportion of patients with total annual income greater than \$50,000 was 62% before diagnosis and 48% following diagnosis. Financial stress was measured before and after diagnosis using a 5-point Likert scale. The mean financial stress level was significantly higher post diagnosis (3.5) compared with pre-diagnosis (2.05) ($P = .0009$).

Patients reported frustration with the inability to work during treatment and attributed many of the difficulties in paying the OOP expenses to the decline in income. Patients' inability to advance their careers, invest in retirement, and accumulate savings for the family were seen as major stress factors. As one participant stated, "Even if I survive the cancer, my quality of life will not be as good because my retirement plan has suffered." The inability to work also seemed to have an impact on patients from a psychological standpoint: "It has been hard to go from the 'breadwinner' in the family to having to rely on others." From a logistic standpoint, several patients reported lack of transparency about the process of filing for disability and were unaware that they would qualify for Social Security disability benefits. At the same time, the process of filing for disability took longer than anticipated, during which period, several individuals faced significant financial hardship: one reported becoming homeless and staying in shelters during this period. Additionally, transitioning back to the workforce from disability was a deterrent for many who worried about a gap in insurance benefits during this time as they went from Medicare coverage back to an employer-based health plan.

Challenges in Navigating and Understanding Health Insurance Plans and Bills

Most patients in this study had either commercial insurance or Medicare with a supplemental plan (66%); however, there were 6 patients (29%)—the majority from HMC—with either Medicaid or institutional charity care coverage. Patients consistently reported difficulty in understanding paperwork and feeling overwhelmed

by Medicare and Medicaid applications, although social workers were usually able to provide guidance and support. Patients also described confusion understanding bills and explanation of benefits and perceived the frequent delays in rendering coverage decisions as “unfair.” Despite the recent Affordable Care Act legislation prohibiting health plans from instituting lifetime coverage limits, many patients also reported fears about hitting a “cap” in spending and being “kicked off” their insurance plan. Finally, many patients reported lack of knowledge about how to navigate between potential insurance plans and how to anticipate higher OOP spending in the “donut hole,” which created tension for some worrying about how to budget other monthly expenses. Switching between insurance plans (eg, moving to a spouse’s plan or transitioning to Medicare) was often associated with large changes in co-payments for chronic medications; these unanticipated changes led to financial difficulties for many patients.

Barriers and Fears About Discussing Costs With Healthcare Providers

Patients were asked a series of questions about their preferences in communicating about costs with their oncologists. Only 12 patients (57%) actually discussed treatment costs with their physicians, which is consistent with previous studies.⁸ Of the 9 patients (43%) who did not discuss treatment costs, 6 reported a treatment-related financial burden of 3 or higher (on a 5-point Likert scale). Information about treatment costs was also not readily available to patients; only 2 patients (10%) reported having prior knowledge of expected costs prior to treatment. Interestingly, only 11 patients (52%) actually believed that physicians should discuss the anticipated costs of treatment with patients prior to making a treatment decision.

When asked more open-ended questions about these discussions, patient responses were mixed. Some patients felt that prior knowledge about anticipated costs would help with short-term and long-term financial planning (eg, monthly budgets, life insurance policy purchasing) and some were amenable to the idea of cheaper treatment alternatives as long as they were “similar in effectiveness” or talking to providers about how to “get the best treatment for less.” One patient stated that “the more information about costs that are exchanged, the more we feel in control.” Other patients viewed prior knowledge of treatment costs as a way of talking to their physicians about “spacing out CT scans” or “evaluating how to avoid duplicating lab draws and imaging tests...the costs of which can add up over time.”

Nevertheless, many patients were strongly against the idea of discussing costs with providers because: 1) cost information would have been overwhelming at diagnosis or 2) they were concerned that discussing costs could influence the physician to offer less-effective treatment. Provocative statements around these concepts include the following:

TABLE 2. Changes in Employment, Income, and Financial Status Before and After Cancer Diagnosis

	Before Diagnosis	After Diagnosis
Employment status		
Employed (part-time or full-time)	18 (86%)	5 (24%)
Unemployed	1 (5%)	1 (5%)
Disability (permanent or temporary)	0 (0%)	10 (47%)
Retired	2 (9%)	5 (24%)
Income		
<\$15,000	3 (14%)	5 (24%)
\$15,000-\$25,000	0 (0%)	3 (14%)
\$25,001-\$50,000	5 (24%)	3 (14%)
\$50,001-\$75,000	2 (10%)	1 (5%)
\$75,001-\$100,000	2 (10%)	4 (19%)
>\$100,000	9 (42%)	5 (24%)
Financial hardships		
Before diagnosis		
Difficulty paying monthly bills	3 (14%)	
Defaults on mortgage payments	1 (5%)	
Credit card debt	4 (19%)	
Bankruptcy	0 (0%)	
At least 1 of the above	4 (19%)	
After diagnosis		
Refinance home		1 (5%)
Sell home		1 (5%)
Sell second home		3 (14%)
Sell stocks/investments		0 (0%)
Use retirement/savings accounts		8 (38%)
Borrow money from friends or family		11 (52%)
Debt (including credit card)		9 (43%) (mean = \$29,857)
Refusing treatment due to cost		6 (29%)
Skipping medication doses due to cost		1 (5%)
At least 1 of the above		16 (76%)
Most burdensome treatment-related costs		
Chemo/hormonal therapy		5 (24%)
Surgery		5 (24%)
Diagnostic testing		4 (24%)
Child care costs		1 (5%)
Transportation costs		5 (24%)
Lost income due to change in employment status		14 (67%)

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TABLE 3. Preferences for Financial Literacy Course Format, Timing, and Content

	Participants (n = 21)
Financial course helpful	
Yes	16 (76%)
No	5 (24%)
Course setting	
Live individual	8 (38%)
Live group	9 (43%)
Online	4 (19%)
Course timing	
At diagnosis	11 (52%)
At start of treatment	1 (5%)
>6 months post diagnosis	4 (19%)
Periodically during treatment	5 (24%)
Course content ranking (4-point scale) (mean score)	
Money management skills	3.14
Resources to help with high co-payments for chemotherapy or other medications	3.67
Choosing an insurance plan and navigating your current insurance coverage	3.43
Resources to help with food, transportation, housing costs	3.09
Financial questions related to clinical trial enrollment	2.6
Strategies to discuss less expensive treatment alternatives	2.79
One-on-one financial counseling with a trained financial adviser	2.86

“Since there is no money and no way to afford the chemotherapy, it is too overwhelming to discuss costs.” “I prefer the doctor’s time to be spent focusing on the cancer and the treatment.” “At diagnosis, I knew that costs would be exorbitant, but I was more concerned at that point about receiving good care.” “I do not think it is the doctor’s responsibility to talk about costs or provide cost information. In fact, it is better for the doctors to be unaware of costs entirely since this information may sway their recommendation.” “When your financial status is not good, it is paralyzing to know the costs in advance.” “I want to survive cancer, so I kind of don’t care how much it costs.” “I don’t want to be shirked on a full diagnosis or full treatment. I will pay the price.”

Finally, many patients simply believed that physicians are a very poor resource for cost information. Patients expressed surprise at the fact that “not even the seller of the service is able to tell you how much it is going to cost you” and that “doctors have no idea about drug costs even when asked directly.” Despite physicians’ lack of knowledge about cost, patients did value recognition of

the financial aspect of treatment: “I do not expect my doctor to be a financial wizard, but I would have liked some acknowledgement that the treatment will have an impact on my financial health as well as my emotional and physical health.”

Preferences for Financial Literacy Course Format and Content

In addition to identifying challenges and barriers to dealing with the cost of cancer treatment, as discussed above, patients were also surveyed about their interest in a financial literacy course and their preferences for course content and timing. A total of 16 patients (76%) reported that a financial literacy course would be helpful, with 43% desiring the course to be administered live in a group setting. Of the 10 patients who did not prefer that physicians should disclose costs with patients prior to treatment, 50% still felt that a financial literacy course would be helpful. Many felt that it would be helpful to learn from others going through a similar situation and might generate discussion that could be relevant to them, and the majority (52%) felt that the course should be administered at the time of diagnosis. Potential course topics of greatest interest to patients are summarized in [Table 3](#).

Realizing that patients often have thought of helpful strategies that providers, investigators, and organizations like CENTS may not have discovered, we asked patients to describe helpful ways in which they previously coped with the cost of cancer treatment. Patients described several strategies, including increasing life insurance policies; eliminating superfluous spending; asking friends for help with meals, transportation, and childcare; using food stamps; comparing pharmacy prices for the same medication; aggressively pursuing resources available through organizations such as Cancer Lifeline, Patient Advocate Foundation, and Patient Access Network Foundation; accepting “donated” work leave; keeping careful records of medical expenses for tax purposes; and utilizing HopeLink transportation assistance. We decided that it would be important to include a discussion of these real-life successful strategies in the course.

Financial Literacy Course Development

Following the feedback obtained through the patient stakeholder interviews, the investigators held a meeting with the CENTS volunteers to debrief and discuss course development in greater detail. We observed that many patients were overwhelmed by treatment costs, but were unwilling to address these concerns at diagnosis due to various reasons. In particular, concerns about receiving lower-quality care were preventing many patients from managing their finances proactively. A required component of the course, therefore, would revolve around bridging the gap between patients and the clinical team about discussing costs.

Although there were several topics appropriate for general discussion in a group setting, other topics more conducive to

1-on-1 discussion included budget planning and providing each patient with individualized OOP treatment cost estimates and detailed insurance plan information. One of CENTS' key services is to provide individualized money management and financial planning services to individuals in a variety of financial situations. Therefore, an optimal course structure would combine a group general informational course and individualized budget planning sessions with a financial expert, incorporating anticipated OOP cost and insurance information. The group also felt it important to involve spouses and other caregivers in the educational process, recognizing the need to relieve the patients of some of the burden. Additionally, partnerships with social workers and billing specialists in the clinic were felt to be critical in navigating patients through the cost of cancer treatment. Specifically, access to patient assistance programs through foundations or pharmaceutical companies, as well as other services (eg, HopeLink transportation services), could be facilitated much more efficiently through the clinic rather than through the CENTS course instructors.

Based on the stakeholder feedback and CENTS expertise, the optimal financial literacy intervention would be a collaborative effort between CENTS, clinical social workers, and clinic billing specialists. The course would be administered to patients newly diagnosed with cancer. The course would address barriers to dealing with treatment costs and address basic information around employment, disability, insurance, and existing assistance resources that all patients should understand. Next, the course would allow 1-on-1 budget planning, incorporating anticipated OOP treatment costs with a trained financial planner. The total course duration would be approximately 2 hours and would be divided between the broader education content and the individualized patient counseling. A course is in development that follows the basic structure outlined in [Table 4](#).

DISCUSSION

In a population of patients with either advanced breast cancer or colorectal cancer—many of whom faced treatment-related financial hardship and stress—there was clear interest in the development of a group financial literacy course. In particular, patient feedback reinforced the importance of addressing the barriers associated with discussing costs with the medical team, the impacts of a cancer diagnosis on employment, navigating health insurance plans, and understanding the available resources for financial assistance (including guidance on disability benefits). Concrete information about anticipated OOP costs and health insurance benefit structure was also thought to be critical in individualized budget and financial planning. It should be noted, however, that this study was limited by its small sample size and the relative underrepresentation of minorities and uninsured individuals. Thus, it is possible that the financial literacy program we develop may not benefit the most disadvantaged patients.

TABLE 4. Proposed Financial Literacy Course Structure

Introductions (including confidentiality assurance)
Addressing barriers to talking about and dealing with treatment costs
Potential impact of cancer treatment on
<ul style="list-style-type: none"> • Savings and retirement • Employment • Budget and other fixed expenses
Understanding employment and disability benefits
Understanding health insurance benefits and interpreting medical bills
Resources for patient assistance
<ul style="list-style-type: none"> • Foundation or pharmaceutical co-payment assistance • Oncology social workers (transportation, meals, housing) • Discussing alternatives to high-cost drugs with physicians • Charity care and disability • Other strategies
Financial planning with cancer
<ul style="list-style-type: none"> • Assets and liabilities • Budgeting • Anticipating income and/or expense changes • Organization • Financial behaviors to avoid • Bankruptcy protection
One-on-one financial planning sessions
<ul style="list-style-type: none"> • Reviewing anticipated treatment out-of-pocket costs • Budget planning • Review health insurance plan details

The financial impact of cancer treatment is a complex problem that is not fully understood. Several groups have attempted to quantify the financial burden of cancer and understand the risk factors for serious financial hardship; however, very few of these studies have been done prospectively in a large, diverse patient population. The first step in alleviating the financial burden of cancer is to characterize the financial impact of cancer treatment more carefully. We are attempting to do this in a planned cooperative group study, which will involve a longitudinal survey assessing baseline financial characteristics, as well as treatment-related financial changes and OOP costs. It is also important to understand that a single intervention is not likely to eradicate the financial burden faced by patients with cancer.

In this study, we focused on empowering patients and increasing knowledge about potential costs with the hope that appropriate financial planning can lessen the financial burden. On the other hand, interventions that help physicians consider OOP costs in treatment decision making could help. Weighing cost into the decisions about palliative chemotherapy with low likelihood of benefit may also reduce the financial impact on these patients nearing the end of life or their surviving family members. On a broader policy level, changes in cost-sharing policies for patients with cancer and changes in drug pricing may help. The expansion of Medicaid to improve access to care in the first place could also help.⁹

CONCLUSIONS

The intent of our study was to understand the need for a financial literacy course and identify important content areas for this course. Further studies aim to measure the impact of this course on OOP expenses and financial hardship in a population of patients newly diagnosed with cancer. To our knowledge, this is one of the first studies to report results from a cancer patient stakeholder-driven financial literacy intervention. ■

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