Bridging the Gap Between Financial Distress and Available Resources for Patients With Cancer: A Qualitative Study

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Abstract

Purpose: Cancer treatment-related out-of-pocket costs create substantial financial distress for many patients. However, little work has been done to describe available financial resources and barriers to connecting those resources to patients.

Methods: This was a single-center, qualitative study that used semistructured interviews and focus groups with social workers and financial care counselors. Interview guides were used to elicit feedback from study participants pertaining to the types of financial problems that their patients were experiencing, the process for addressing these issues, patient assistance resources, and access barriers.

Results: Four interviews and two focus group sessions (n = 15) were conducted in which four themes emerged among the

social work and financial care counselor samples. Participants cited (1) frustration over the lack of financial resources and increasingly stringent eligibility criteria, (2) barriers to providing assistance such as process inefficiencies, (3) limited resources to identify at-risk patients and refer them for services, and (4) inadequate insurance coverage and availability. To bridge the gap between increasing patient need and limited resources, participants suggested development of interventions designed to aid in patient screening and resource identification.

Conclusions: Oncology social workers and financial care counselors reported inadequate financial resources and faced barriers to matching appropriate resources with patients in need. Limited social work resources hindered early screening for financial distress. Interventions that focus on screening for early identification of financial distress and identification of resources are needed.

Introduction

Although patients with cancer continue to benefit from innovations in treatment, those innovations have come at a cost. As health care costs have risen, insurers have shifted some of the cost burden to consumers. A recent report by the Economic Policy Institute¹ stated that most cost-sharing proposals lead to higher out-of-pocket medical costs, hitting those who require a high degree of medical care especially hard and likely leading to future financial risk.

The rising financial burden of cancer care is well known to health professionals who work in oncology; a recent study by the Association of Oncology Social Work (AOSW) reported that the majority of patient participants indicated that cancer costs negatively affected their focus on recovery.² Sixty-six percent of patients with major financial challenges reported depression or anxiety symptoms, 29% delayed filling prescriptions as a result of financial pressures, and 22% skipped doses of their medications. In addition, 40% reported depleting their savings in the past year to pay for cancer-related costs.

Financial distress may be considered an adverse effect of treatment that can affect patient well-being and quality of care (previously described as “financial toxicity”).³ However, it is incompletely addressed in a health care system that provides limited resources for financial assistance.

Furthermore, little work has been done to describe what financial resources are available for patients undergoing cancer treatment, or how those charged with providing patients assistance do so with the resources at hand. In this context, we

sought to better understand how social workers and financial care counselors on the front lines of cancer care interact with patients in financial need. The aim of this qualitative study was to describe financial assistance resources available to social workers and financial care counselors at a referral cancer center. We explored related issues such as barriers to access and patient eligibility for assistance.

Methods

This was a single-institution, qualitative study of resources available to social workers and financial care counselors at the Duke Cancer Institute in Durham, NC. This study was approved by the Duke University Medical Center Institutional Review Board.

Social Work Interviews

To develop a basis for focus group discussion points, four 1-hour, in-person interviews with five oncology social workers were conducted over a 1-month period. An interview invitation and consent form were e-mailed to all oncology social workers. Respondents were scheduled for a 1-hour time slot at a private location of their choosing (eg, their office). A social work research scientist (S.K.S.) conducted individual, face-to-face interviews. Data were recorded using field notes and subsequently coded. A semistructured interview guide was used to collect information regarding the financial assistance process, resource availability and provision by insurance type, the most commonly requested assistance and related barriers, and additional

resources that would be helpful in reducing patients' treatment-related financial burden (Data Supplement).

Focus Groups

After completion of preliminary interviews, invitations to participate in the focus groups were e-mailed to all oncology social workers and financial care counselors, with a publication from a related study on cancer treatment-related costs attached for their reference.³ Respondents were notified of the time and location of their social work or financial care counselor focus group session. Semistructured guides based on the face-to-face interview results were used to elicit information from the participants regarding typical assistance required by patients with cancer, barriers to delivering financial assistance, access to necessary resources, and potential interventions that might improve financial assistance capabilities (Data Supplement). The principal investigator (S.Y.Z.) moderated the focus groups; the assistant moderators (S.K.S., J.N.) took observational notes at each of the sessions. The number of focus groups held was predetermined, and discussion within each group was encouraged for each question until no new views were expressed by study participants.

Analysis

Field notes were compared and contrasted between the five interviews and two focus group sessions and later combined. To become familiar with the data, all coinvestigators read and reread field notes from the interviews and focus group sessions per the steps outlined by Kruger.^{4,5} Next, we revisited the study purpose and questions, analyzed and compared our findings, identified common themes, and selected example quotes. Differences were discussed until agreement was reached by all.

Results

Four in-person interviews with five social workers were conducted (100% response rate); one of the interviews was conducted with two social workers. The mean numbers of years spent in an oncology and general social work role were 6.3 and 11.6 years, respectively. The social workers represented the following adult oncology programs: bone marrow transplant, brain tumor, gynecologic oncology, inpatient oncology, and outpatient oncology.

Two focus group sessions were held. The first was conducted with eight financial care counselors representing the following adult oncology programs: brain tumor, breast, endocrine, gastrointestinal, genitourinary, hematologic malignancies, melanoma, thoracic, and oncology treatment center. The second session was held with seven oncology social workers representing the following adult oncology programs: brain tumor, breast, genitourinary, gynecologic oncology, hematologic malignancies, inpatient hospital, and outpatient clinic.

Thematic analysis suggested four themes were shared between the social work and financial care counselor samples. Study participants (1) were frustrated over the lack of financial

resources and increasingly stringent eligibility criteria; (2) faced institutional barriers to obtaining assistance, such as process inefficiencies; (3) had inadequate resources to identify and refer for services and needed additional help; and (4) were limited by the patients' insurance coverage.

Financial Resource Availability and Provider Frustrations

The most frequent out-of-pocket assistance requests were for prescription drug copayments; insurance premiums (eg, COBRA); and travel expenses including gas, lodging, parking, and food. Of these, study participants had the most success securing provisions for copayments and travel expenses; however, most requests went unfulfilled. Insurance premium support was cited as the most difficult to secure. Other needs such as time off work, dental assistance, utility and housing costs, unexpected events (eg, automobile repairs, catastrophe), medical supplies (eg, wigs, prosthetics), housework, and private duty care were also cited by the social workers as being difficult to address.

Social workers reported several industry and nonprofit organizations that provided financial support to patients with cancer (Table 1). Pharmaceutical companies were cited as providing the majority of drug copayment assistance, whereas visit copayment and insurance premium payment assistance were limited and disease-specific. Nonprofit organizations such as the American Cancer Society provided assistance for out-of-pocket expenses related to travel, special dietary needs, and alternative therapies, but the availability of funds has been largely curtailed due to the economic downturn, according to participants.

The most frequent frustration cited by social workers was the lack of readily available financial resources.

Social worker: "There used to be more resources – not any longer. Patients only get bits and pieces of support. Foundations are a moving target with eligibility criteria that are constantly changing."

Financial care counselor: "Foundations run out of money by May, so you have to wait the rest of the year until the till fills up again."

Social worker: "We feel so helpless as there are no resources to work with. Patients are losing their homes to pay for their treatment and are forced to live in their automobiles."

Social workers also expressed displeasure with the tightening eligibility criteria based on income, disease type, or sex. For example, one major nonprofit agency requires that the patient earn below 200% of the federal poverty guideline (ie, \$44,100 for a family of four) to be eligible for financial assistance of \$100. Due to lack of aid, patients are at risk for noncompliance:

Social worker: "We often hear that our patients can't afford their oral medications, so they cut them in half sometimes."

Furthermore, Medicaid Social Security Disability Insurance requires a "spend down"⁶ before resources kick in (ie, many patients have too much income to qualify for Medicaid but may qualify if they spend the excess income on medical bills). In

Table 1. Financial Resources Available to Oncology Patients

Expense	Resources
Prescription drug co-pays	Income-based. Social work is the gatekeeper. Pharmaceutical companies provide support (mostly to uninsured patients); additional programs available: Leukemia/Lymphoma (LL), Patient Advocacy (PAF).
Visit co-pays	Very limited: LL, PAF, Cancer Care (CC), Co-Pay Relief Foundation (< \$1,000). Physicians may also choose to override charges.
Insurance premium payments	LL, Healthwell, Patient Assistance Organization.
Travel expenses (including parking, lodging, fuel, and meal costs)	American Cancer Society (\$50 gas card, Road to Recovery), CC (multiple myeloma only). Medicaid reimburses lodging and mileage (not covered by Medicare).
Time off work compensation	Short- or long-term disability insurance received prior to cancer.
Special dietary expenses	Hospital dietitians are free. BOOST indigent programs, food stamps, National Marrow Program, Caring Community Foundation.
Alternative therapy expenses	Hospital social work and patient support services are free of charge. Blue Cross discount on acupuncture.
Medical equipment costs	Private insurance and Medicaid covers well (eg, Medicaid pays 100%; Medicare, 80%).
Nonprescription drug costs	One-time, limited resource in social work department (up to \$50) if it helps to avoid hospitalization.
Private duty nursing care	Only covered under private pay long-term insurance.

addition, trying to reach the Medicaid customer service is difficult at best (ie, no call-backs, delayed wait times). Other frustrations included lack of temporary and semipermanent lodging:

Social worker: “It would be awesome . . . if we had a place where patients could stay. Even \$40/night is difficult to cover.”

Process Inefficiencies and Barriers to Obtaining Resource Provisions

Social workers noted that patient financial education is delivered early in the care trajectory, at a time when patients are overwhelmed with the diagnosis and unable to register any financial concerns; therefore, potential financial issues are not pre-empted.

Social worker: “We tend to get them at crisis. It is time consuming to continue addressing issues in emergency mode.”

Patients expressed reluctance to discuss money issues with their physician to study participants out of fear that it could impact their care or due to embarrassment.

Financial care counselor: “Many patients are too embarrassed to ask for help.”

Financial care counselor: “Many patients have their pride hurt when Medicaid is suggested to them.”

In some cases, the institutional infrastructure was cited as a barrier.

Social worker: “Our clinic is a barrier as well – patients don’t know how to find us.”

Financial care counselors indicated that many patients are enrolled in the wrong insurance plan, suggesting educational barriers are present.

Financial care counselor: “We like to see our patients early in their diagnosis so that we can help them switch to the right insurance plan. What works for 25-year-olds doesn’t usually work for 55-year-olds.”

Furthermore, study participants expressed concern that the financial assistance information patients are accessing on the Internet can be misleading and/or inaccurate.

Limited Resource Availability for Screening and Identification of Financial Assistance

Social workers have limited resources to identify and refer patients for additional help, particularly for patients with poor-quality insurance.

Social worker: “It is difficult to identify underinsured [patients] at midincome level. There are triggers to identify when social work is needed such as at reoccurrence.”

Although patients who require financial assistance are referred to social work by their clinician, those patients are often unaware of what is available to them in terms of assistance.

Financial care counselor: “Patients don’t know what to ask for in the way of resources.”

Social worker: “There is a gap between what patients need and what they ask for.”

Social workers valued administering a psychosocial assessments and/or algorithms to assess the patient’s financial situation. However, social workers reported not having enough time in their day to address all of their patients’ cancer-related needs.

Social worker: “We don’t get to work on psychosocial issues as we are slammed with addressing basic needs.”

Insurance Coverage Limitations

According to participants, the coverage provided by private insurance varies widely depending on the plan type (eg, some have large deductibles). Of the government-sponsored insurance plans, Medicare was cited as having the least provisions (ie, only pays 80% of treatment, with no prescription coverage), and Medicare plus supplemental was viewed in a more positive light. In addition, study participants reported that Medicaid covers all medical costs but only for in-state patients. This presented a problem for a referral center where patients are seen from wide catchment areas.

Financial care counselor: “Patients who have out-of-state insurance or Medicaid don’t qualify for assistance – their providers have to be willing to refer that patient out, and many don’t.”

Furthermore, study participants cited that “the bar has been raised” for Medicaid eligibility.

Financial care counselor: “It is much harder to qualify for Medicaid now. For example, land owners and patients who have two vehicles are no longer eligible.”

Participants noted that many patients lose their jobs as a result of their cancer, resulting in loss of or limitations to insurance coverage.

Financial care counselor: “Many patients lose their jobs due to cancer. Then they try to get insurance but it costs so much with high deductibles. So they come in with poor insurance and companies won’t pay.”

Financial care counselor: “Caregivers and patients get pressured from employers for losing time off work.”

Financial care counselor: “Caregivers are losing money because they are losing a day of work to help with the patient’s appointment.”

Ideas for Improvement

Enhancing the delivery of resources to patients. The use of patient navigators, a financial distress screening tool, counselors to refer patients, and customer service staff were cited as ways to enhance the delivery of financial resources to patients. In addition, sending a parking ticket and lunch voucher in a first-visit mailing, installing signs to notify patients of where to purchase a discounted parking coupon booklet, parking assistance funding, expanding options for housing patients locally, education on Medicare and Medicaid, having on-site billing staff, and communicating with patients early in treatment regarding insurance issues were suggested.

Better targeting resources to improve efficiencies. A social worker suggested developing a reliable database of financial resources that could be accessed by patients and providers. Another stated that creating a “big pot of money” for patients to use for out-of-pocket expense would help to streamline efficiencies and get out of crisis/emergency mode. In addition, bundling out-of-pocket costs into treatment cost estimates, conducting needs assessments, providing personalized resource binders, conducting weekly phone check-ins, improving coordination with financial care counselors, educating physicians on the cost of medications, and meeting patients at diagnosis to provide financial education were suggested.

Exploring the use of screening to serve as a bridge between social work and technology. Social workers suggested improving efficiency through the use of e-screening tools that are completed by all patients at certain time points through the care continuum.

Additional resources and comments. The study participants suggested many ways to improve the financial health of their patient population. Recommendations such as fund-raising events for daily needs such as lodging support (in addition to funding treatment), enlisting community help for rides to and from the airport, putting resource information online, identifying financial needs early in the survivorship trajectory through

screening and development of a prediction algorithm, and lobbying for a local American Cancer Society–sponsored “Hope Lodge” (ie, no-cost lodging). It was also noted that patients approach and often receive financial assistance from their family, friends, and churches.

Discussion

The main finding from this single-institution study is that the availability of financial resources is limited; many barriers exist that prevent patients with cancer from accessing the resources that are available. Study participants cited common out-of-pocket expenses such as prescription drug co-payments, insurance premiums, and travel. However, resource limitations (eg, stringent eligibility criteria, decreasing funds), barriers to access (eg, limited social work resources to identify and refer for services, patient reluctance to discuss financial distress with their health care team), and process inefficiencies often lead to unmet needs.²

Our finding of limited financial resources is not surprising. A growing literature reports on the problem of increased out-of-pocket expenditures coinciding with decreased resource availability among patients with cancer and their families.⁷⁻¹¹ For example, Davidoff et al¹² found that the mean out-of-pocket spending for cancer patients was \$4,727 and that 28% of Medicare beneficiaries with cancer experienced a significantly high financial burden compared with 16% of Medicare beneficiaries without cancer. Importantly, our study adds a first-person perspective from those on the front line of providing assistance to underinsured patients with cancer.

In terms of barriers to access, we found infrastructure and process inefficiencies, insurance issues, and lack of social work resources to screen for financial distress to be the most cited by our study participants. In addition, the reported reluctance of patients to discuss their financial distress coupled with the lack of comprehensive patient screening capabilities further adds to the problem of unmet needs. Furthermore, these barriers were reported to affect patients’ families as well. For example, our findings related to caregivers (eg, lost income and/or insurance coverage) are consistent with those reported in a review of the economic burden of caring for people with cancer.¹³

These results are subject to limitations. First, this was a single-institution study at a referral center. Although generalizability may be limited, our findings are consistent with those of the AOSW study² in echoing the voices of social workers and financial care counselors who are struggling to help patients with financial needs. Also, this study adds to the AOSW study by enhancing the understanding of financial resource availability and related access barriers incurred by those who help care for patients with cancer. Second, one or more dominant participants could have influenced the individual responses from within the two focus groups, thus potentially contributing to bias in the results. However, the principal investigator and co-moderators are experienced in conducting focus groups and took great effort in minimizing this effect by encouraging all focus group members to contribute to the discussion regardless of competing views. Third, the lack of audio recording and

transcription of the data could affect the accuracy of the data analyzed. However, verbatim transcription is not always required,¹⁴ and extensive field notes were taken by the principal investigator and co-moderators in the interviews and focus groups.

Health care policy and coverage in the United States is evolving, but the effect of the Affordable Care Act on cost of care—rather than access—remains unknown. Regardless, patients with cancer today continue to struggle with financial distress associated with care, as evidenced by the findings in this study (eg, lack of financial resources, barriers to achieving resource provisions, insurance coverage issues). In addition, some patients are driven to spend retirement savings or declare bankruptcy as a result of mounting health care bills.^{3,15} Research should focus on developing interventions to (1) identify patients at risk for financial distress and (2) inform patients of potential resources specific to their financial needs. Future studies should consider including social workers and financial care counselors for their unique perspective on the problem of cancer treatment-related financial distress. As one social worker put it, “If we were able to address the [financial] issues up front, it would prevent problems down the road.”

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Authors' Disclosures of Potential Conflicts of Interest

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