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Article

Delivery of Financial Navigation Services Within National Cancer Institute–Designated Cancer Centers

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Abstract

Background: Cancer centers have a responsibility to help patients manage the costs of their cancer treatment. This article describes the availability of financial navigation services within the National Cancer Institute (NCI)–designated cancer centers. Methods: Data were obtained from the NCI Survey of Financial Navigation Services and Research, an online survey administered to NCI–designated cancer centers from July to September 2019. Of the 62 eligible centers, 57 completed all or most of the survey, for a response rate of 90.5%. Results: Nearly all cancer centers reported providing help with applications for pharmaceutical assistance programs and medical discounts (96.5%), health insurance coverage (91.2%), assistance with nonmedical costs (96.5%), and help understanding medical bills and out-of-pocket costs (85.9%). Although other services were common, in some cases they were only available to certain patients. These services included direct financial assistance with medical and nonmedical costs and referrals to outside organizations for financial assistance. The least common services included medical debt management (63.2%), detailed discussions about the cost of treatment (54.4%), and guidance about legal protections (50.1%). Providing treatment cost transparency to patients was reported as a common challenge: 71.9% of centers agreed or strongly agreed that it is difficult to determine how much a cancer patient's treatment will cost, and 70.2% of oncologists are reluctant to discuss financial issues with patients. Conclusions: Cancer centers provide many financial services and resources. However, there remains a need to build additional capacity to deliver comprehensive financial navigation services and to understand the extent to which patients are referred and helped by these services.

Individuals diagnosed with cancer are at risk for financial hardship as a result of the cost of their cancer care (1,2). The launch price of new cancer therapies has risen exponentially over the last decade, and the prices of both patented drugs and generic drugs tend to increase over time (3-5). The impact of treatment costs on the patient and health-care system is further amplified because patients are increasingly prescribed combination therapies, often taking multiple drugs simultaneously, while remaining on active treatment for extended periods of time (4,6). Trends in health benefit designs including, but not limited to, high deductible health plans and tiered formularies have resulted in often unmanageable patient out-of-pocket costs because of higher deductibles and cost sharing, especially for specialty tier drugs such as targeted oral anticancer medications (7,8). Additionally, the side effects and time demands associated with cancer treatment can directly interfere with work ability for the patients and their caregivers, which can adversely affect household finances and access to employer-sponsored health insurance (9-12).

Because of this constellation of factors, more than half of individuals with cancer report financial hardship as a result of their cancer care, comprising the collective impact of out-of-pocket costs and lost income, psychological worry about finances, and behavioral coping responses that include delaying or foregoing recommended care and other necessities to save money (13-16). The consequences of financial hardship are wide ranging and can result in diminished quality of life for patients and their families, poor patient outcomes and, in extreme cases, premature death (17-20).

Clinicians, other health-care providers, and health-care delivery systems have a unique opportunity to help patients anticipate and manage the cost concerns of cancer treatment. The prevalence and impact of financial hardship among patients with cancer underscore the importance of identifying patients with financial need and delivering financial navigation and counseling services to help patients understand and manage their out-of-pocket expenses for medical care (21-25). Although there is

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some evidence that financial navigation interventions are helpful to patients, few evidence-based models of financial navigation exist, and accumulating evidence highlights barriers to delivering comprehensive financial navigation services within health-care settings (25-31).

In an effort to characterize the landscape of financial services available to cancer patients and their families and better understand system-level barriers to delivering those services, we conducted a survey of the National Cancer Institute (NCI)–designated cancer centers to characterize the availability of services and supportive resources for addressing financial concerns, the staffing model for delivering those services, and the barriers centers encounter in providing financial navigation to their patients.

Methods

Survey and Sample

Data were obtained from the NCI Survey of Financial Navigation Services and Research, administered to NCI–designated cancer centers from July to September 2019. The sample for this survey comprised the NCI–designated cancer centers that provide patient care (32). Of the 62 centers invited to participate, 57 centers completed all or most of the survey items for a response rate of 90.5%.

The survey consisted of 16 multiple choice and open-ended items examining the prevalence of financial navigation services offered, related care delivery and staffing models, barriers to providing financial navigation, and engagement in cancer-related financial navigation research (Supplementary Material, available online). Survey questions were informed by the literature and developed with input from NCI staff, individuals with expertise in survey design, and external subject matter experts, including several clinicians and health services researchers who had active research programs focused on aspects of cancer-related financial hardship. E-mails announcing the survey were first sent to each cancer center director and associate director for administration. Next, e-mails containing an invitation to participate and link to the survey were sent to the associate directors in charge of population sciences. These 3 leadership positions are common to each NCI–designated cancer center. Surveys were completed by the associate director for population sciences or a different staff member designated by them, the cancer center director, or the associate director for administration. Respondents were encouraged to consult others in their institution for assistance gathering information to complete the survey; however, each center completed a single survey. Nonresponders received up to 4 e-mail reminders and 1 telephone reminder during the data collection period. No honorarium was provided, although all cancer centers, regardless of participation, received a report summarizing survey results. This study was exempt from human subjects review.

Measures and Data Analysis

Financial service. Centers were asked about the availability of 10 different services and whether they were available to either all patients or certain patients based on cancer type or treatment. Services ranged from assistance with medical bills, debt, and health insurance (help understanding medical bills and out-of-pocket costs, counseling about medical debt management, help applying for health insurance, and direct assistance paying for medical care), assistance with nonmedical costs and referrals (direct financial assistance with nonmedical costs such as transportation, housing, utility bills, and other expenses; help applying for financial assistance with nonmedical costs; referrals to a foundation or charity for financial navigation), guidance about legal protections for cancer patients and their families, treatment cost transparency, and pharmacy discounts.

Staffing model. Centers were asked which staff provided each service they offered. Options included a financial navigator, patient navigator, social worker, case manager, doctor, nurse, advance practice provider, pharmacy staff, billing staff, and other. Centers could indicate multiple staff delivered each service, and results are presented for the 3 staff positions mentioned most frequently for each service.

Experiences. Centers were asked about their agreement with a set of 9 questions about barriers to the delivery of financial navigation services. Questions covered the availability of services, staff awareness and capacity to coordinate services for patients, the difficulty determining treatment costs, the complexity of applications for financial assistance, oncologists' reluctance to discuss financial issues with patients, patients' reluctance to ask for help, and the workflows to connect patients with existing services. Responses were scored on a 5-point Likert scale but collapsed into 3 categories: strongly agree or agree, neither agree or disagree, and disagree or strongly disagree.

Owing to the small sample size, analyses were descriptive, with frequencies and proportions provided for each question.

Results

Availability of Financial Navigation Services

Cancer centers provide a range of financial navigation services to their patients (Table 1). Certain services were widely available to all patients. Nearly all centers self-reported that they make help available to all patients to understand medical bills and anticipate out-of-pocket costs (85.9%) as well as help patients apply for pharmaceutical assistance programs and medical discounts (96.5%), financial assistance with nonmedical costs (96.5%), and health insurance coverage (91.2%). Other services were offered by the majority of centers, but in some cases, availability was limited to certain patients based on their cancer type and treatment. For example, 77.2% of centers made referrals to outside organizations for financial assistance available to all patients with an additional 17.5% of centers making this service available to certain patients. Additionally, 56.1% of centers made direct financial assistance available to all patients to help pay for medical care with an additional 26.3% making this service available to certain patients. The availability of other services was more variable. When looking at the combined total of centers that offered services to either all patients or certain patients based on their cancer type or treatment, 63.2% of centers provided counseling about medical debt management, 54.4% provided detailed discussions about treatment options, including a comparison of costs, and 50.9% provided legal protections to cancer patients and their families.

Staff Involved in Providing Financial Services

Our survey suggested that different staff are involved in delivering financial navigation services (Table 2). Assistance managing medical bills, debt, and health insurance was most frequently provided by financial navigators, billing staff, and social workers. Assistance with nonmedical costs and referrals was most frequently provided by social workers, financial navigators, and patient navigators. Guidance about legal protections was most frequently provided by social workers, financial navigators, and other staff. Discussions to improve treatment cost transparency was provided by financial navigators, doctors, and advance practice providers. Assistance with pharmacy discounts was most frequently provided by pharmacy staff, financial navigators, and social workers. The staff mentioned most frequently across services were financial navigators, who commonly provide all services mentioned, and social workers, who commonly provide 9 of the 10 services mentioned.

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Table 1. Financial navigation services available to patients treated at National Cancer Institute–designated cancer centers

Financial navigation service	% Available to all patients	% Available to certain patients based on cancer type or treatment	% Not available/ "I don't know"
Help applying for pharmaceutical assistance programs and medication discounts	96.5	1.8	1.8
Help applying for financial assistance with nonmedical costs such as transportation, housing, utility bills, and other expenses	96.5	1.8	1.8
Help applying for health insurance coverage, including Emergency Medicaid	91.2	3.5	5.3
Help understanding medical bills and out-of-pocket costs or the projections of what those costs are expected to be	85.9	3.5	10.5
Referrals to a foundation or charity for financial navigation or help paying for medical care	77.2	17.5	5.3
Direct financial assistance with nonmedical costs such as transportation, utility bills, housing, and other expenses	68.4	19.3	12.3
Counseling about medical debt management	57.9	5.3	36.8
Direct financial assistance paying for medical care, including the costs associated with participating in a clinical trial	56.1	26.3	17.5
Guidance about legal protections for cancer patients and their families	45.6	5.3	49.1
Detailed discussions about treatment options, including a comparison of costs	40.4	14.0	45.6

Barriers to Financial Navigation

Cancer centers reported challenges with delivering financial navigation services (Figure 1). The barriers most consistently endorsed by centers were that it is difficult to determine how much a cancer patient's treatment will cost and oncologists are reluctant to discuss financial issues with cancer patients, statements with which more than 70% of centers agreed or strongly agreed. More than two-thirds of centers also agreed or strongly agreed that applications for financial assistance are complex and time consuming. However, in other domains, experiences across centers was more variable, with responses reflecting very different experiences in the areas of staff awareness and capacity to deliver financial navigation. For example, 45.6% of centers agreed or strongly agreed that the pathways or workflows to connect patients with existing services were unclear; yet, 26.3% of centers disagreed or strongly disagreed with that statement. Likewise, less than half of centers agreed or strongly agreed with the statements: staff do not have enough time to coordinate financial navigation services for cancer patients (43.9%), there is a lack of staff awareness about available financial navigation services for cancer patients (40.4%), there are few financial navigation services to offer cancer patients (40.4%), and staff are not equipped to discuss finance issues with cancer patients (38.6%). Yet, between 38.6% and 49.1% of centers reported that they disagreed or strongly disagreed with these same statements.

Discussion

The growing prevalence and substantial impact of cancer-related financial hardship is increasingly well documented (33,34). The escalating cost of cancer treatment along with commensurate increases in patients' out-of-pocket costs have resulted in a need for comprehensive financial services to support cancer patients and their families (24,35). NCI-designated cancer centers are in a unique position to deliver comprehensive models of financial hardship screening, navigation, and services, given the large population that they serve. The findings from this survey suggest that cancer centers offer a large suite of services and resources to patients and their families to prevent and mitigate the impact of high cancer treatment costs, making assistance managing medical bills, debt, and health insurance; nonmedical costs and referrals; and assistance with pharmacy discounts widely available to all patients. These services address key drivers of patient out-of-pocket costs and are important for both preventing and mitigating cancer-related financial hardship.

However, centers do report challenges with delivering financial navigation services. Our findings highlight a need for research that can inform strategies to proactively address treatment costs and related concerns early in the treatment planning process, build staff capacity to address financial issues, and establish workflows and referral pathways to identify patients experiencing financial need and to deliver financial services. Future research should inform approaches to systematically identify patients in need and explore how administrative data and other existing information about insurance status, employment, and patient-level characteristics can be used for financial hardship screening. Likewise, interventions are needed that will build on existing center (or delivery system) capacity to enhance the scope and reach of financial navigation and improve the coordination and delivery of existing services (21,28). The few published trials of financial navigations as well as the broader patient navigation literature provide important lessons and models for coordinating care and connecting patients with the resources they need (27,29,31,36-38). This is particularly crucial in the era of COVID-19, where many individuals with cancer are grappling with employment disruption as well as increased vulnerability to the virus and impacts on cancer treatment, in some cases (39).

Our survey identified 3 common barriers to cost transparency and proactively addressing patients' cost concerns: it is difficult to estimate treatment costs for individual patients, oncologists are reluctant to discuss financial issues with patients, and patients are reluctant to ask for help when they need it—findings that have been echoed in other studies (25,40-45). These results underscore the need for research to streamline the calculation of patient costs or other approaches to help convey the approximate cost for different treatment regimens. Because cancer therapy frequency includes multiple treatment modalities, administered over a long period of time, future research should inform best practices for estimating accumulating treatment costs and communicating this information to patients.

To ensure that information is made available to patients when they need it, role delineation is needed to identify which members of the

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Table 2. Staff who provide financial navigation services within National Cancer Institute–designated cancer centers

Financial navigation service	Staff who most often provide service (%)[a]					
Medical bills, debt, and health insurance						
Counseling about medical debt management	Financial navigator	(77.8)	Billing staff	(44.4)	Social worker	(36.1)
Help understanding medical bills and out-of-pocket costs or the projections of what those costs are expected to be	Financial navigator	(86.3)	Billing staff	(56.9)	Social worker	(43.1)
Help applying for health insurance coverage, including Emergency Medicaid	Financial navigator	(68.5)	Social worker	(53.7)	Billing staff	(31.5)
Direct financial assistance paying for medical care, including the costs associated with participating in a clinical trial	Financial navigator	(61.7)	Social worker	(48.9)	Billing staff	(36.2)
Nonmedical costs and referrals						
Direct financial assistance with nonmedical costs such as transportation, utility bills, housing and other expenses.	Social worker	(90.0)	Financial navigator	(30.0)	Patient navigator	(30.0)
Referrals to a foundation or charity for financial navigation or help paying for medical care	Social worker	(72.2)	Financial navigator	(48.1)	Patient navigator	(25.9)
Help applying for financial assistance with nonmedical costs such as transportation, housing, utility bills, and other expenses	Social worker	(92.7)	Financial navigator	(34.5)	Patient navigator	(30.9)
Legal protections						
Guidance about legal protections for cancer patients and families	Social worker	(62.1)	Financial navigator	(44.8)	Other	(37.9)
Treatment cost transparency						
Detailed discussions about treatment options, including a comparison of costs	Financial navigator	(61.3)	Doctor	(38.7)	Advance practice provider	(29.0)
Pharmacy discounts						
Help applying for pharmaceutical assistance programs and medication discounts	Pharmacy staff	(51.8)	Financial navigator	(46.4)	Social worker	(41.1)

[a]Staff are limited to the 3 positions reported most frequently by participating cancer centers. Staff are listed in descending order, based on how frequently they were reported as offering a financial navigation service.

health-care team should initiate and follow up on cost discussion and research to ensure that information is communicated in a clear, accessible, and actionable way. Consistent with recommendations from the American Society of Clinical Oncology and others, these conversations should address both the direct costs of care (eg, co-pays, deductibles, uncovered expenses) and the indirect costs of care (eg, lost time from work, transportation) as well as the value of different treatment recommendations, framed in terms of anticipated benefit relative to costs (46,47). Finally, to remove the burden on patients to initiate cost conversations and alleviate concerns that less expensive treatment equates to suboptimal outcomes, systematic screening for financial concerns is also necessary to direct appropriate services and should be part of clinical care.

Although a variety of staff are involved in providing financial navigation services within NCI-designated cancer centers, for nearly all the services we asked about, financial navigators and social workers were identified by centers as being among the top 3 staff to provide that service. Capacity among staff in these positions, however, may be stretched given the multitude of other responsibilities. There is a need to expand the number of individuals in these positions and streamline financial navigation services. In addition, innovative models of team-based care and training for navigators and social workers, as well as nurses who are less often involved in financial conversations, could enhance the ability and capacity to address financial hardship with a greater number of patients.

Nearly half of centers agreed or strongly agreed that the pathways to connect patients with existing services were unclear and that staff lack sufficient time and capacity to coordinate financial services for patients. Further, centers reported that applications for financial assistance are complex and time consuming, which may further interfere with patients' access to assistance (48-50). Our results suggest that the delivery of financial services is fragmented. The responsibility for assessing financial hardship and delivering financial assistance services spans different staff and departments, often with no clear formal coordination or communication. In addition, financial navigation and services delivered often differ by cancer type and clinic based on resources and knowledge of providers and staff. In addition to building capacity among staff who are involved in delivering financial services, there is a need to improve clinic workflows and referral patterns to ensure that patients are identified and referred for services in an efficient and coordinated way.

To mitigate cancer-related financial hardship, a pipeline of research to develop and test models of financial navigation and implementation science to ensure the dissemination of effective interventions is critical. Likewise, existing evidence-based models must be scaled up and tailored to different settings. In particular, there is need to build capacity for offering those services that are not widely available. For example, consistent with other studies, our survey suggested a need to expand guidance about legal protections for patients and their families. Such guidance is particularly relevant for employed cancer patients and their families who may need to take leave from work or require accommodations to remain at or return to their jobs and who may need help navigating their rights under the Family Medical Leave Act, the Americans with Disability Act,

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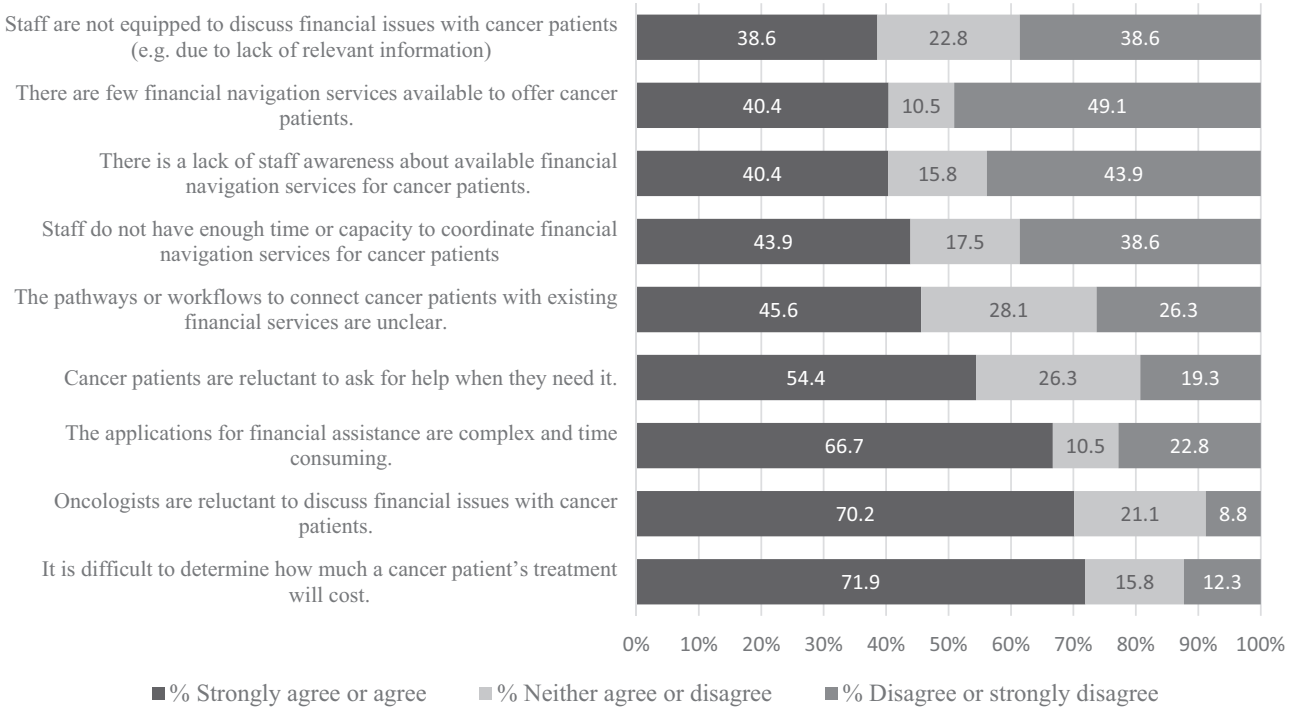

Figure 1. Barriers to delivering financial navigation services within National Cancer Institute–designated cancer centers.

and Consolidated Omnibus Budget Reconciliation Act, as well as other protections (51-54).

There are several limitations to the survey that should be considered when interpreting the findings. Respondents completing the survey at each center may have had varying perspectives and knowledge about the availability and delivery of financial navigation services. Thus, the findings may not fully reflect all the financial services available and the scope of challenges around financial service delivery. Likewise, for questions about oncologist- and staff-level barriers to financial navigation, findings may partially reflect respondents' broader awareness of the scientific literature in addition to their knowledge about local challenges. Additionally, findings are based on self-report; NCI did not externally validate the availability of financial navigation services or how those services are delivered. The survey also did not capture the availability of financial navigation services from the patient's perspective. Although the survey provides information about what services are available through NCI-designated cancer centers, it does not describe what services patients use or find helpful. The survey does not tell us who is functioning as a financial navigator or anything about their training and background, only that staff in these roles are broadly involved in delivering financial services.

Finally, the NCI-designated cancer centers are affiliated with university medical centers, and they represent a variety of treatment settings across the United States (32). However, the data from this survey may not generalize to community cancer centers or other settings that differ in size, patient population, and resources (21).

This study provides a baseline assessment of the financial services and supportive resources offered at NCI-designated cancer centers across the United States. Our results indicate that centers deliver many financial services but with great variability and despite several challenges with delivery. The increase in number of people diagnosed with cancer each year, coupled with rising costs of cancer care for cancer patients and survivors, points to an even greater need to provide comprehensive financial services throughout treatment and survivorship care (55,56).

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Disclaimer: The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the National Cancer Institute.

Data Availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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