Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

HHS Public Access

Author manuscript

J Cancer Surviv. Author manuscript; available in PMC 2023 October 01.

Published in final edited form as:

J Cancer Surviv. 2023 October ; 17(5): 1461–1470. doi:10.1007/s11764-022-01175-2.

Financial Navigation Staff Perspectives on Patients' Financial Burden of Cancer Care

CPCRN Rural Cancer Workgroup,

Katherine A. Yeager[1], **Whitney E. Zahnd**[2,3], **Jan M. Eberth**[3], **Robin C. Vanderpool**[4], **Catherine Rohweder**[5], **Randall Teal**[5], **Maihan Vu**[5], **Lindsay Stradtman**[4], **Elizabeth Frost**[6], **Erika Trapl**[6], **Sarah Koopman Gonzalez**[6], **Thuy Vu**[7], **Linda K. Ko**[7], **Allison Cole**[7], **Paige E. Farris**[8], **Jackilen Shannon**[8], **Natoshia Askelson**[2], **Laura Seegmiller**[2], **Arica White**[9], **Jean Edward**[4], **Melinda Davis**[8], **Victoria Petermann**[5], **Stephanie B Wheeler**[5]

[1]Emory University

[2]University of Iowa

[3]University of South Carolina

[4]University of Kentucky

[5]University of North Carolina at Chapel Hill

[6]Case Western Reserve University

[7]University of Washington

[8]Oregon Health & Science University

[9]Centers for Disease Control and Prevention

Abstract

Purpose: To describe perceptions of financial navigation staff concerning patients' cancer-related financial burden.

Methods: This qualitative descriptive study used a semi-structured interview guide to examine perceptions of financial navigation staff concerning patients' cancer-related financial burden. Staff who provided financial navigation support services to cancer patients were interviewed from different types of cancer programs across seven states representing rural, micropolitan, and urban settings. Interviews lasted approximately one hour, were audio recorded, and transcribed. Transcripts were double coded for thematic analysis.

Corresponding author— Katherine A. Yeager, kyeager@emory.edu, 404-727-8627.

Authors Contribution:
Zahnd, Eberth, Vanderpool, Rohweder, Vu(T), Ko, Askelson, Petermann, Wheeler, Shannon, Davis, and Farris contributed to study concept and design. Zahnd, Eberth, Vanderpool, Rohweder, Stradtman, Frost, Trapl, Gonzalez, Vu (T), Ko, Cole, Askelson, Seegmiller, Petermann, Shannon, Davis, and Farris participated in data collection. Yeager, Teal, Vu (M) completed the data analysis. All authors contributed in drafting and revising the manuscript and approved the final version.

Competing Interests:
The authors have no relevant financial or non-financial interests to disclose

Results: Thirty-five staff from 29 cancer centers were interviewed. The first theme involved communication issues related to patient and financial navigation staff expectations, timing and the sensitive nature of financial discussions. The second theme involved the multi-faceted impact of financial burden on patients, including stress, difficulty adhering to treatments, and challenges meeting basic, non-medical needs.

Conclusions and Implications for Cancer Survivors: Cancer-related financial burden has a profound impact on cancer survivors' health and non-health outcomes. Discussions regarding cancer-related costs between cancer survivors and healthcare team members could help to normalize conversations and mitigate the multi-faceted determinants and effects of cancer-related financial burden. As treatment may span months and years and unexpected costs arise, having this discussion regularly and systematically is needed.

Keywords

cancer; communication; finances; treatment costs

INTRODUCTION

With the continued rise in cancer care costs, including high-priced cancer drugs, financial burden is well-documented among cancer survivors in the United States [1]. Cancer treatment costs contribute to the financial toxicity experienced by cancer patients, especially as insurance co-pays and out of pocket (OOP) costs increase and employment and related income adjustments occur [1]. OOP cost burden extends beyond medical expenses and includes non-medical expenses as well, such as having to pay for housing, transportation, and support services related to treatment. For patients who live far distances from cancer treatment centers, travel costs including transportation, lodging, and parking fees can be exorbitant [2,3].

The impact of the high OOP costs associated with cancer care was demonstrated by Zafar et al. [4], who showed that 42% of cancer patients reported a significant or catastrophic financial burden; 68% of patients cut back on leisure activities, 46% reduced spending on food and clothing, and 46% used savings to defray OOP expenses. Patients with a high financial burden were also more likely than those without high financial burden to forego a recommended test or procedure or skip an appointment. To save money, 20% took less than the prescribed amount of medication, 19% partially filled prescriptions, and 24% avoided filling prescriptions altogether [4]. Moreover, greater financial burden among individuals with cancer is associated with greater symptom burden and decreased quality of life [5]. Additionally, extreme financial distress requiring bankruptcy protection after cancer diagnosis is a risk factor for mortality [6].

Although dedicated financial navigation programs are not standard in all oncology settings, nearly all cancer centers strive to provide some type of assistance to patients related to their financial concerns [7]. In settings with formal financial navigators on staff, financial support staff serve as the primary contact for fielding questions and aiding patients who are experiencing financial burdens and employment issues associated with cancer treatment [8,9]. In other settings, clinical nursing staff or social workers take on the responsibility of

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

assisting patients with financial issues. Overall, the oncology community has increasingly recognized that helping patients manage financial burden is an essential component of care for patients undergoing cancer treatment [10]. Although this work is done by a variety of professionals, in this paper, we collectively refer to all of these individuals providing financial support services as financial navigation staff despite differences in titles or credentials. Little is known about the perspectives of these staff acting as financial navigators and their views of cancer patients experiencing financial burden. The purpose of this paper is to describe perceptions of financial navigation staff at cancer centers concerning patients' cancer-related financial burden. This information is needed to determine the best strategies to help cancer patients struggling with financial burden and to inform intervention development and best practices.

METHODS

This qualitative study was conducted through the Cancer Prevention and Control Research Network (CPCRN), a multicenter collaborative network funded by the U.S. Centers for Disease Control and Prevention (https://cpcrn.org/). The CPCRN includes academic, public health, and community partners working together to reduce the burden of cancer care, especially among underserved populations. This study was designed and conducted by a cross-CPCRN workgroup comprising seven participating CPCRN sites in 2018. We conducted and analyzed semi-structured interviews with staff from diverse cancer care programs located in Iowa, Kentucky, North Carolina, Ohio, Oregon, South Carolina, and Washington. This study was classified as expedited or exempt by the institutional review boards (IRBs) at all seven CPCRN sites.

Participant Recruitment

To create the sampling frame, study team members at each CPCRN site independently identified programs in their state that provided cancer care (at hospitals and free-standing clinics) through public websites, state cancer registries, statewide cancer consortia, and cancer center networks. Purposeful sampling was used throughout the seven states involved to select participants from institutions across the rural–urban continuum and from different types of facilities, including National Cancer Institute (NCI)-designated cancer centers, Commission on Cancer (CoC)-accredited and non-CoC accredited centers, and free-standing cancer clinics. Using U.S. Department of Agriculture's 2013 Rural-Urban Continuum Codes (RUCC), facilities were categorized as urban/metro (RUCC 1-3), micropolitan (RUCC 4-6), or rural (RUCC 7-9).

Next, potential study participants within each program were identified by reaching out to professional networks (e.g., relationships with American Cancer Society regional managers, state cancer registry staff, hospital system staff) or by calling cancer centers directly. If an individual indicated interest in participating, a CPCRN study team member provided a study information sheet and scheduled a phone or in-person interview.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Data Collection

All interviews were conducted by trained research team members from the seven CPRCN sites from December 2018 through June 2019 using a semi-structured interview guide. This guide was developed by the study team and then pilot-tested with three cancer care program staff members at different locations to assess length of the interview and clarity of questions. The interview guide included questions about methods used for assessing financial distress, perceived financial burdens of cancer patients, strategies used to help patients locate and apply for financial support, and perspectives on how financial stress influences patients' cancer care. Before starting the interview, the researchers reviewed the study purpose and obtained consent for the interview to be audiotaped.

A Qualtrics survey was used to collect data on participant characteristics (age, sex, race/ethnicity, educational attainment, time worked at current location, and prior financial navigation training) and cancer program characteristics (program type, presence of a National Community Oncology Research Program (NCORP)), extent of catchment area, treatment services provided, special populations served, and location (metropolitan, micropolitan, rural). Interviews lasted approximately 60 minutes with a range of 30 to 90 minutes. All interviews were digitally recorded, and files were transcribed verbatim by a professional service.

Data Analysis

Transcripts were imported into Dedoose (http://www.dedoose.com), a qualitative research software that can be used to organize data, after a member of the study team de-identified interview text. Research team members developed an initial codebook based on review of transcripts, the interview guide, and the research questions. The initial codebook was pilot tested independently by two coders, which led to refining and clarifying some of the code definitions and decision rules. The final version of the codebook was then applied to the remaining interview transcripts. All transcripts were independently coded by two research team members who followed standard coding guidelines [11]. Coders identified themes, and discrepancies were reconciled by discussion and consensus. Analysts generated code reports from Dedoose and wrote narrative summaries for each code, which were then synthesized into a narrative description of the themes. A key summary report was developed that included a narrative description of the themes and sub-themes along with illustrative quotes.

The descriptive data focused on participant and institution characteristics and were summarized by calculating mean ± standard deviation (SD) for continuous variables and frequency (%) for categorical variables.

RESULTS

Cancer Program and Participant Characteristics

Thirty-five participants participated in the interviews; demographic and institutional characteristics are summarized in Table 1. Nearly half (46%) of participants were 40-49 years of age and were primarily female (89%) and White (89%). Over one-third (37%) of

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

participants had training in social work, about half (46%) had a master's degree or higher, and two thirds (63%) had worked at their institution more than 5 years.

Participants worked at 29 unique cancer care programs/sites in seven states. Of the 29 sites, 6 (21%) were NCI-designated cancer centers, 13 (45%) were non-NCI designated, CoC-accredited facilities, 8 (28%) were non- CoC-accredited facilities, and the remaining 2 (7%) were freestanding clinics (Table 1). Less than half (45%) of participants interviewed were from programs in metro counties. Two-thirds of participants (66%) worked in facilities with a catchment area that included multiple counties. Fewer than half of facilities (48%) provided psycho-oncology services.

Two key themes describe financial navigation staff perspective of cancer patients' experiences dealing with financial challenges. The first theme involved communication issues related to patient and financial navigation staff expectations, timing of financial discussions, and the sensitive nature of these discussions. The second theme involved the multi-faceted impact of financial burden on patients, including stress, difficulty adhering to treatments, and challenges meeting basic, non-medical needs.

Theme One: Communication Issues Related to Expectations, Timing, and the Nature of Discussions about Financial Issues

Participants discussed a spectrum of cancer patient expectations regarding provider communication about financial issues (Table 2). Although financial support staff often reported that their patients did not see financial discussions as part of their providers' role, several mentioned there had been instances when patients voiced frustration about their providers not talking to them about financial issues, usually pertaining to prior authorization requirements or not knowing how much treatment was going to cost. Financial navigators felt there was a disconnect between the providers and patients, and the lack of discussion by providers about cancer care costs with patients caused frustration for the financial navigation staff. Participants indicated providers were focused primarily on treating the patient and, often, did not fully grasp how much a given procedure or medication would cost or what kind of insurance coverage a patient had or patient OOP costs for treatment. Participants felt that providers saw 'financial discussions' with patients as largely the job of the financial navigators/counselors or social workers. However, a few participants shared that the providers at their institution were aware of financial costs and tried to tailor treatment plans to what a patient could or could not afford. Pharmacies were also mentioned as locations where cost issues were discussed with patients.

Many participants indicated that patients were not fully aware of how the payment for services worked and what options were available to them at intervenable times during their treatment. Therefore, the participants felt that the timing of the discussion about financial issues was important to consider. For example, discussing financial issues during a time when the patient is less overwhelmed and more fully informed about their condition would enable patients to better advocate for themselves about treatment decisions. However, a few participants mentioned that because most patients were unaware of the cost of their cancer care and insurance coverage, it was better to have a financial conversation early in the treatment process. Additionally, participants recognized the sensitive nature of discussions about finances; sometimes pride or shame served as barriers to asking for help.

Theme Two: Multi-faceted Impact of Financial Stress on Cancer Patients

Participants discussed different ways cancer-related financial burdens had affected their cancer patients' overall health. Key topics included the financial navigation staff perception of the stress experienced by patients, consequences of this stress, impact on lack of adherence to cancer treatment, and challenges to meeting non-medical basic needs (Table 3). A few participants shared they experienced very few, if any, instances when a patient was negatively affected by their cancer care–related financial situation. However, most participants indicated that the patients they worked with experienced significant medical and non-medical financial challenges.

Stress experienced by patients: Participants discussed how stress related to financial concerns during cancer treatment affected the patients' psychological and physical wellbeing. They described seeing patients receive medical bills in the middle of treatments, potentially adding to the patients' baseline stress related to cancer treatment. Participants witnessed patients negotiating how they were going to pay their medical bills or continue to work, and speculated that this situation made it more difficult for the patients to focus and process all of the information they were receiving about their cancer diagnosis and treatment.

Difficulties adhering to treatments: Participants discussed different observations of patients coping with their financial concerns, including altering their treatment plans or stopping, delaying, or skipping cancer treatments. Patients would reduce their dosage of medications, stop taking them altogether, or miss appointments to reduce the expense of cancer care. Before treatment initiation, some patients decided to decline treatment completely because they were worried that they could not afford it, sometimes before allowing the support staff to explore all potential areas of financial assistance. For some patients, concerns about going into debt guided their decisions to decline, delay or stop treatment. One participant described a patient who stopped treatment because he had lost his job and wanted to wait until he found a new job and had insurance. Interview participants voiced frustration that patients would make these decisions without telling clinical staff, pre-empting the opportunity to explore supportive options to continue their treatment. Participants recognized that these tough decisions about treatment and choosing to delay treatment probably happened more frequently than they were aware, since often patients simply did not show up for scheduled clinic appointments. Participants also specifically mentioned challenges with medication adherence due to financial concerns, whether for oral chemotherapy or other prescription medications. This scenario included patients skipping doses so the medication they had would last longer. Participants expressed concern about how these treatment delays or skipped medications could affect efficacy of the treatment.

Meeting basic non-medical needs: A final area of concern discussed by participants was how the cost and demands of cancer care affected patients' abilities to meet their basic non-medical needs. They indicated that patients worried about how to pay for housing,

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

utilities, groceries, and travel costs. Specific to employment, patients risked losing their jobs because of missed work due to treatment, which could cascade into additional worries over the potential of losing employment-based health insurance. Family members also risked losing jobs when they were responsible for transportation of their family member receiving cancer care. Patients losing their homes and becoming homeless or having to move in with family members were profound examples of the effect of the cost of cancer care on daily life.

Discussion

In our study, financial navigation staff reported that most cancer patients did not think providers should be responsible for discussing cost or financial concerns; however, financial support staff noted that some provider awareness and communication with patients about this issue would be helpful, at a minimum, to inform treatment planning and referrals to financial support staff. A study by Pisu and colleagues report that providers were not perceived by patients to be the appropriate personnel to discuss costs with patients since their focus should be medical care while clinical visit time constraints act as a barrier to initiating these discussions [12]. However, other research has found that patients expect this communication from their oncologist [13-15]. Interview participants recognized the need to clarify who is responsible for which aspects of communication around financial issues.

Our results also highlight that the timing of the discussion around financial support is important and that the sensitive nature of topic requires a directed discussion in a private setting. Research by Pisu and colleagues found discussions need to occur when patients are ready [12, 16]. Others feel that the conversation should occur after the visit in which they are informed of the diagnosis but before treatment starts. Work by Zafar suggests that once patients deplete their savings during the course of treatment, patients’ interest in discussing cost with health care providers increases [17]. As treatment may span months and years and unexpected costs arise, having this discussion regularly and systematically with all patients could help to normalize such conversations.

Findings from our study further illustrate the stress experienced by patients and consequences of this stress, including inability to continue cancer treatment, and challenges to meet basic needs. These themes are similar to domains of financial hardship described by Altice and colleagues who characterize financial hardship as 1) the psychological response to the increase in expenses that are part of the cancer experience, 2) the coping behaviors that patients adopt to manage their medical care while experiencing increased expenses during cancer care, and 3) material conditions that arise from the increased expenses and lower income related to the cancer experience [1]. The stress of financial hardship can exacerbate the stress from the cancer experience whether soon after the diagnosis, during the treatment planning phase, or throughout the cancer survivor continuum. The interaction between stress from financial burden and treatment or cancer symptoms most likely magnify the stress of the cancer experience [18]. Regular, reoccurring discussions and dedicated support to manage patients’ financial burden are examples of supportive interventions that could help alleviate some of the associated stress. Additionally, the effect on the family and costs related to caregiving needs further exploration [19].

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Financial navigation staff described how patients coped with their financial concerns by declining, stopping, or delaying cancer treatment as well as missing medications and appointments. These activities are similar to the coping strategies discussed in a recent systematic review that described the financial hardship experienced by cancer survivors. Their findings highlight survivors with higher levels of financial hardship are at greater risk of treatment nonadherence and delaying or forgoing medical care altogether [1]. Alarming patterns of treatment nonadherence are concerning in that nonadherence can decrease treatment efficacy and result in worse patient outcomes. For example, in chronic leukemia oral chemotherapy agents, 90% adherence is needed to obtain a response resulting in improved patient survival [20]. Thus, addressing financial hardship for cancer patients is critical to ensuring the delivery of equitable, quality cancer care.

Our findings highlight the stark sacrifices patients make due to financial burden while managing cancer care including difficulty meeting basic non-medical needs. Examples include cancer patients cutting back on household budgets, restricting career/self-advancement, depleting savings and choosing which bills to pay and which not to pay [21]. These sacrifices illustrate the daily struggles that can arise after a cancer diagnosis. Additionally, the continuum of the cancer experience, including diagnosis and treatment through survivorship or end-of-life care, requires cancer patients to continually examine their socioeconomic situation alongside everyday life and family obligations.

Implications

Over ten years ago the American Society of Clinical Oncology developed a guidance statement on the cost of cancer care, identifying conversations about cost between oncologist and patients as a key component of high-quality cancer care [22]. Despite this guidance, financial concerns of patients are often not addressed in the clinical setting and their needs go unmet [23-26]. Our findings demonstrate that more than a decade later, there is still a disconnect between the oncologist’s perceived role in cancer care and the services available to patients to help negotiate the financial costs of cancer care and associated sequelae (e.g., challenges meeting health related social needs).

Communication from the entire care team about cancer care costs and financial issues in the early stages of the cancer diagnosis and throughout the treatment process is important. Whether the physician, pharmacist, nurse practitioner, social worker, financial navigator, or support staff begin the discussion, addressing cancer patient concerns and needs throughout the cancer continuum could help to alleviate stress for the patient. A team approach could be an effective means of providing individualized care to assist patients with their financial needs including assessment of needs in areas such as prescription drug copayments, insurance premiums, travel expenses, and employment issues [27]. Financial navigators, if available, can lead the discussion, but having all team members aware of and helping to address financial hardship/stress could lead to better outcomes. Helping patients enroll in patient assistance programs, sometimes called medication assistance programs [10], is one step in a critical multi-pronged approach. Financial navigation training for staff would improve communication so that patients’ needs are met. All cancer patients could participate in conversations with trained staff to review estimates of anticipated OOP costs

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

and insurance coverage in a sensitive manner to provide reassurance, sympathy, and concrete solutions [28].

Limitations and Strengths

This study provided the perspective of staff focusing on financial needs of patients from a range of cancer care settings across seven states. Although this study has considerable strengths, this study also has limitations. We interviewed cancer care program staff about their perceptions of patient experiences of financial burden rather than patients themselves. Therefore, the interviews represent the overall experience of the staff members and does not provide firsthand accounts from the patients themselves and limits our understanding how patients came to make decisions about their treatment or how they decided to navigate financial costs. Future work could incorporate additional perspectives from patients and providers. Although patients can provide first-hand accounts of how the cost of cancer care has financially affected them, it is important to understand cancer care program staffs' perceptions of patient needs as we work to improve financial support structures.

Conclusions—Given these findings, thoughtfully designed interventions would help to address the common patient experiences of financial burden that financial navigators report. Unfortunately, little work has been done to develop and test interventions. Shankaran and colleagues report on development of an oncology financial navigation program to improve patient knowledge about treatment costs, provide financial counseling, and help manage OOP expenses. Their pilot study demonstrated feasibility and decreased anxiety about costs over time for one third of their sample, but self-reported financial burden did not change [29]. Another study showed financial guidance and assistance through specially trained navigators at four hospitals benefitted patients through decreased OOP expenditures and mitigated financial losses for the participating hospitals [30]. Increased knowledge about financial coping behaviors that families use to cope during cancer care will be especially useful in developing interventions to improve completion of recommended treatment [1]. Overall cancer-related financial stress can have a profound impact on cancer survivors' treatment and outcomes and can be addressed by the health care team.

Funding:

This publication is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award with 100 percent funded by CDC/HHS (Cooperative Agreement Number U48 DP006377, U48 DP006389, U48 DP006400, U48 DP006401, U48 DP006398, 3 U48 DP005030-01S5, 3 U48 DP005006-01S3, 3 U48 DP005014-01S2). The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention. Additionally, Dr. Davis was partially funded by a National Cancer Institute Career Development Award (K07CA211971)." And Ms. Petermann was funded by the Cancer Control Education Program T32 (T32CA057726-27)

Data Availability

Data is being de-identified and can be made available upon publication.

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

References

1. Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR (2017) Financial hardships experienced by cancer survivors: A systematic review. J Natl Cancer Inst 109 (2). 10.1093/jnci/djw205
2. Lee A, Shah K, Chino F (2020) Assessment of parking fees at National Cancer Institute-designated cancer treatment centers. JAMA Oncol 6 (8):1295–1297. 10.1001/jamaoncol.2020.1475 [PubMed: 32672809]
3. Rocque GB, Williams CP, Miller HD, Azuero A, Wheeler SB, Pisu M, Hull O, Rocconi RP, Kenzik KM (2019) Impact of travel time on health care costs and resource use by phase of care for older patients with cancer. J Clin Oncol 37 (22):1935–1945. 10.1200/JCO.19.00175 [PubMed: 31184952]
4. Zafar SY, Peppercorn JM, Schrag D, Taylor DH, Goetzinger AM, Zhong XY, Abernethy AP (2013) The financial toxicity of cancer treatment: A pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. Oncologist 18 (4):381–390. 10.1634/theoncologist.2012-0279 [PubMed: 23442307]
5. Lathan CS, Cronin A, Tucker-Seeley R, Zafar SY, Ayanian JZ, Schrag D (2016) Association of financial strain with symptom burden and quality of life for patients with lung or colorectal cancer. J Clin Oncol 34 (15):1732–1740. 10.1200/jco.2015.63.2232 [PubMed: 26926678]
6. Ramsey SD, Bansal A, Fedorenko CR, Blough DK, Overstreet KA, Shankaran V, Newcomb P (2016) Financial insolvency as a risk factor for early mortality among patients with cancer. J Clin Oncol 34 (9):980–986. 10.1200/JCO.2015.64.6620 [PubMed: 26811521]
7. de Moor JS, Mollica M, Sampson S, Adjei B, Weaver S,Geiger AM, Kramer BS, Grenen E, Miscally E, Ciolino HP (2021) Delivery of financial navigation services within National Cancer Institute-designated cancer centers, JNCI Cancer Spectrum, 10.1093/jncics/pkab033
8. Spencer JC, Samuel CA, Rosenstein DL, Reeder-Hayes KE, Manning ML, Sellers JB, Wheeler SB (2018) Oncology navigators' perceptions of cancer-related financial burden and financial assistance resources. Support Care Cancer 26 (4):1315–1321. 10.1007/s00520-017-3958-3 [PubMed: 29124417]
9. Vanderpool RC, Nichols H, Hoffler EF, Swanberg JE (2017) Cancer and employment issues: Perspectives from cancer patient navigators. J Cancer Educ. 2017 Sep;32(3):460–466. 10.1007/s13187-015-0956-3. [PubMed: 26627904]
10. McMullen L (2019) Patient assistance programs: Easing the burden of financial toxicity during cancer treatment. Clinical journal of oncology nursing 23 (5):36–40. 10.1188/19.cjon.s2.36-40
11. Creswell JW, Poth CN (2018) Qualitative inquiry and research design choosing among five approaches. 4th edn. SAGE Publications, Inc., Thousand Oaks
12. Pisu M, Schoenberger YM, Herbey I, Brown-Galvan A, Liang MI, Riggs K, Meneses K (2019) Perspectives on conversations about costs of cancer care of breast cancer survivors and cancer center staff: A qualitative study. Ann Intern Med 170 (9_Suppl):S54–s61. 10.7326/m18-2117 [PubMed: 31060056]
13. Bullock AJ, Hofstatter EW, Yushak ML, Buss MK (2012) Understanding patients' attitudes toward communication about the cost of cancer care. Journal of Oncology Practice 8 (4):e50–58. 10.1200/jop.2011.000418 [PubMed: 23180999]
14. Henrikson NB, Tuzzio L, Loggers ET, Miyoshi J, Buist DS (2014) Patient and oncologist discussions about cancer care costs. Support Care Cancer 22 (4):961–967. 10.1007/s00520-013-2050-x [PubMed: 24276955]
15. Kelly RJ, Forde PM, Elnahal SM, Forastiere AA, Rosner GL, Smith TJ (2015) Patients and physicians can discuss costs of cancer treatment in the clinic. Journal of Oncology Practice 11 (4):308–312. 10.1200/jop.2015.003780 [PubMed: 26015459]
16. Pisu M, Henrikson NB, Banegas MP, Yabroff KR (2018) Costs of cancer along the care continuum: What we can expect based on recent literature. Cancer 124 (21):4181–4191. 10.1002/cncr.31643 [PubMed: 30475400]
17. Zafar SY, Chino F, Ubel PA, Rushing C, Samsa G, Altomare I, Nicolla J, Schrag D, Tulsky JA, Abernethy AP, Peppercorn JM (2015) The utility of cost discussions between patients with cancer and oncologists. The American Journal of Managed Care 21 (9):607–615 [PubMed: 26618364]

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript

18. Chan RJ, Gordon L, Zafar SY, Miaskowski C (2018) Financial toxicity and symptom burden: what is the big deal? Support Care Cancer 26 (5):1357–1359. 10.1007/s00520-018-4092-6 [PubMed: 29435714]
19. Coumoundouros C, Ould Brahim L, Lambert SD, McCusker J (2019) The direct and indirect financial costs of informal cancer care: A scoping review. Health & Social Care in the Community 27 (5):e622–e636. 10.1111/hsc.12808 [PubMed: 31293013]
20. Marin D, Bazeos A, Mahon FX, Eliasson L, Milojkovic D, Bua M, Apperley JF, Szydlo R, Desai R, Kozlowski K, Paliompeis C, Latham V, Foroni L, Molimard M, Reid A, Rezvani K, de Lavallade H, Guallar C, Goldman J, Khorashad JS (2010) Adherence is the critical factor for achieving molecular responses in patients with chronic myeloid leukemia who achieve complete cytogenetic responses on imatinib. J Clin Oncol 28 (14):2381–2388. 10.1200/jco.2009.26.3087 [PubMed: 20385986]
21. Banegas MP, Schneider JL, Firemark AJ, Dickerson JF, Kent EE, de Moor JS, Virgo KS, Guy GP Jr., Ekwueme DU, Zheng Z, Varga AM, Waiwaiole LA, Nutt SM, Narayan A, Yabroff KR (2019) The social and economic toll of cancer survivorship: a complex web of financial sacrifice. J Cancer Surviv 13 (3):406–417. 10.1007/s11764-019-00761-1 [PubMed: 31123985]
22. Meropol NJ, Schrag D, Smith TJ, Mulvey TM, Langdon RM Jr., Blum D, Ubel PA, Schnipper LE (2009) American society of clinical oncology guidance statement: The cost of cancer care. J Clin Oncol
23. Harrington NG, Scott AM, Spencer EA (2020) Working toward evidence-based guidelines for cost-of-care conversations between patients and physicians: A systematic review of the literature. Soc Sci Med. 2020 Aug;258:113084. . 10.1016/j.socscimed.2020.113084. [PubMed: 32569948]
24. Jagsi R, Ward KC, Abrahamse PH, Wallner LP, Kurian AW, Hamilton AS, Katz SJ, Hawley ST (2018) Unmet need for clinician engagement regarding financial toxicity after diagnosis of breast cancer. Cancer 124 (18):3668–3676. 10.1002/cncr.31532 [PubMed: 30033631]
25. Rai A, Zheng Z, Zhao J, de Moor JS, Ekwueme DU, Yabroff KR (2020) Patient-provider discussions about out-of-pocket costs of cancer care in the U.S. Am J Prev Med 59 (2):228–236. 10.1016/j.amepre.2020.02.017 [PubMed: 32417019]
26. Yabroff KR, Bradley C, Shih YT (2020) Understanding financial hardship among cancer survivors in the United States: Strategies for prevention and mitigation. J Clin Oncol 38 (4):292–301. 10.1200/jco.19.01564 [PubMed: 31804869]
27. Nichols HM, Swanberg JE, Vanderpool RC. Patient-provider communication: Experiences of low-wage-earning breast cancer survivors in managing cancer and work. J Cancer Educ. 2019 Jun;34(3):542–549. 10.1007/s13187-018-1338-4. [PubMed: 29480506]
28. Pisu M, Banegas MP, Liang MI, Tuzzio L, Henrikson NB (2020) How, when, and with whom should cost of care conversations occur? Preferences of two distinct cancer survivor groups. JCO Oncol Pract:Jop1900726. 10.1200/jop.19.00726
29. Shankaran V, Leahy T, Steelquist J, Watabayashi K, Linden H, Ramsey S, Schwartz N, Kreizenbeck K, Nelson J, Balch A, Singleton E, Gallagher K, Overstreet K (2018) Pilot feasibility study of an oncology financial navigation program. Journal of Oncology Practice 14 (2):e122–e129. 10.1200/jop.2017.024927 [PubMed: 29272200]
30. Yezefski T, Steelquist J, Watabayashi K, Sherman D, Shankaran V (2018) Impact of trained oncology financial navigators on patient out-of-pocket spending. The American Journal of Managed Care 24 (5 Suppl):S74–s79. [PubMed: 29620814]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Table 1:

Participant and Cancer Program Characteristics

Participant Characteristics	**N (%) (n=35)**
Age	
<40	9 (26%)
40-49	16 (46%)
50-59	4 (11%)
60+	5 (14%)
Did not answer	1 (3%)
Female, Yes	31 (89%)
Hispanic Status, Yes	1 (3%)
Race	
White	31 (89%)
Black/African American	3 (8%)
Other	1 (3%)
Discipline in which training occurred	
Social Work	13 (37%)
Nursing	5 (14%)
Finance/Business	8 (23%)
Other	9 (26%)
Highest Degree Obtained	
Some College/Associate’s Degree	7 (20%)
Bachelor’s Degree	12 (34%)
Master’s Degree or Higher	16 (46%)
Number of Years Working at Current Site	
1-2 Years	6 (17%)
3-4 Years	7 (20%)
5-6 Years	5 (14%)
7-10 Years	7 (20%)
10+ Years	10 (29%)
Type of Training Received for Role	
Training from Formal Degree	17 (49%)
Training from Accredited Program	10 (29%)
On the Job Training	6 (17%)
Self-Study	11 (31%)
No Specific Training	5 (14%)
Other	16 (46%)
Cancer Program Characteristics	**(n=29)**
Cancer Program Type	
NCI-designated	6 (21%)
Non-NCI designated, CoC-accredited	13 (45%)

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Participant Characteristics	**N (%) (n=35)**
Non-CoC-accredited	8 (28%)
Free Standing	2 (7%)
Rural-Urban Continuum Code of Site Location	
1-3 (urban/metro)	13 (45%)
4-6 (micropolitan)	10 (34%)
7-9 (rural)	5 (17%)
Multiple	1 (3%)
NCORP Site, Yes	11 (38%)
Catchment Area Size	
Single County	6 (21%)
Multiple Counties	19 (66%)
Entire State/Multiple States	4 (14%)
Treatment Services Provided (check all that apply)	
Blood and/or Marrow Transplant	11 (38%)
Chemotherapy (Infusion)	29 (100%)
Chemotherapy (Oral)	28 (97%)
Clinical Trials	16 (55%)
Immunotherapy	24 (83%)
Psycho-oncology Services	14 (48%)
Radiation Oncology	23 (79%)
Supportive Treatments (Complementary/Palliative Services)	19 (66%)
Surgical Oncology	21 (72%)
Number of Financial Navigation Staff at Cancer Program	
0	7 (24%)
1-3	17 (59%)
4+	5 (17%)
Services/staff that address financial assistance for cancer care (in addition Financial Navigation Staff)	
Social Workers	6 (21%)
Nurses (Navigators, Case Manager)	5 (17%)
Other Navigation/Counseling	8 (28%)
Pharmacists	2 (7%)
Billing or Other Office Support	4 (14%)
Internal Programming	12 (41%)
External Programming	3 (10%)

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Table 2.

Communications about Financial Issues

Theme	Representative Quote (Cancer Program Type, RUCC)
Patient expectations	I've actually had several patients that get upset at the doctors when they first meet them for the consult never had said anything to them about the cost. A lot of patients want to know before they consent to treatment how much stuff is going to be? FSC_6
	I don't think the patients feel like it is the providers role. Actually, I mean, our pharmacy often picks up that piece. If it's the medication, they end up talking with them about the financial concerns or applying for this or that or copays or what not. It seems to the pharmacy that might pick that up as the provider person that would talk about it, but I don't hear from patients that they wish their provider would have talked about it. COC_RUCC_6
Providers role /not involved	No, I don't think from what I have talked to patients is that providers usually do not talk to them about financial stuff at all. They rarely even know what's paying for the visit or what insurance they have. So when they have frustrations, it's usually outside of the provider office and being referred someplace that may be the clinic refers them someplace that doesn't take their coverage or doesn't have charity care. They have barriers to that care because nobody is identifying what their financial situation is. COC_RUCC_3
	I would say that they're not really talking about it. I think that our providers don't talk about it. I think that they just send us in and say,"Figure it out with them." I don't think that they understand that we have limitations. It's not like we can replace someone's like full salary for six months, you know? We don't have that. What does that look like? COC_RUCC_2
Providers role /involved	And I've got one provider that calls me and he's like, "You know, this is the treatment plan that I'm thinking. Patient's self-pay. I need you to get drug replacement so that I can get this patient on you know, this. "And it's, like [laughs], "Okay". But he is actually very aware of what the cost are, and that that's gonna be an issue. And so, he's kind of like the standard that you want your docs to be, because he does, he actually will call me and say, "This is my treatment plan. How can we make that happen"? COC_RUCC_3
Lack of patient knowledge	Well, and a lot of people are not insurance savvy, and so, they think they've got Medicare so Medicare is gonna pay for everything. Not realizing with just straight Medicare, that there's, like, no cap. So, it's 80/20, but that 20 percent goes on forever and ever. Whereas, with commercial insurances or some of the HMOs, there's actually an out of pocket maximum that you reach, and then you don't have any more than that amount of money. And so, I mean, people have never heard of the word – you know, explanation of benefits, that's just that annoying piece of paper that they get. And all of a sudden you're asking them to pay attention to that, and to be aware of what that is, and deductibles, and out of pocket maximums, and all these words they've never really considered before. COC_RUCC_3
Sensitive topic to discuss/difficult to disclose	There's a lot of patients that have never had to ask for help in their lives, that this affects, and all of a sudden they feel like they're asking for welfare. I had a patient just crying when I was talking to him about, "You know, this is what I do, and not that you're gonna need it, but this is what I do." And he started crying and he was, like, "I've never had to ask for help before. I don't understand how I'm gonna do this," because he couldn't work. I mean, radiation is every single day and sometimes for six weeks. And so, you know, it certainly cuts down on the paycheck. And when you're living paycheck to paycheck successfully, something like this makes it almost impossible to maintain that. COC_RUCC_3
	But we also in looking at things, when people are asked to disclose their financials, if we're gonna try to get them help, a lot of them don't wanna disclose it because you know, they've got the family farm that's gonna be inherited for the children and they're thinking about that and they really are afraid to discuss what assets they have. Because they don't wanna lose that family farm. Some of them are to the point thinking, I'm sixty years old. I've lived a good life. I wanna leave everything to my children so I won't do anything. I'm not going to even try to get help for this. It's cheaper if I don't. It's tragic. COC_RUCC_7

Abbreviations: COC=Commission on Cancer accredited, non-COC=non-Commission on Cancer accredited), RUCC=Rural-Urban Continuum Code

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Table 3.

Impact on patients : Stress, treatment adherence and meeting basic needs

Theme & Sub-Themes	Representative Quote (Cancer Program Type, RUCC)
Stress	
Overload/ cumulative stress—impacting health	Well, a lot of our patients the only thing they're – they come to us very anxious and very upset and worried because they don't have insurance…I think a lot of times they're not able to really grasp what's going on with their disease because they are so worried about the financial part of it. COC__RUCC_3
	I have patients who were struggling with mental health and then, when you added financial distress, it increased their thoughts of suicidal ideation. These are kind of extreme cases, but it's what I've seen. COC_RUCC_6
	Well, I feel like that it affects their quality of life. Obviously if they're stressed, I don't know if it's a proven or not but I feel like when a patient is stressed and depressed about different things, I feel like it makes their quality of life go down. They don't fight as hard for their cancer. Or for their disease that they're trying to get cured of, or just to stay alive. I feel like that's a biggie. NCOC_RUCC_7
Effects ability to process info	And I see patients stressing about that piece, so when you're talking to them about what's going on with their cancer, and what's going on with their bodies, and the changes they may ____, they're not hearing any of it. It's a barrier to even understand, to being able to process any of that. Because all they're hearing is, "How am I gonna pay?" You know, I'm not gonna be able to work. How am I goon pay for this" And so, they can't even – you know, it's Maslow's Hierarchy of Need, they can't even get to the place where they're processing the disease itself, because they're so worried about the finances do. And that's a very real part of what we do and what we see. COC_RUCC_3
Treatment adherence	
Deciding not to start treatment	It affects them mentally, physically – I mean, if they have an issue with – I've had patients say, well, I can't afford this so I'm not going to do treatment. I've had patients turn down treatment because they didn't think they could afford it. And that breaks my heart when they do that. But you can't force them to do it either. CoC_RUCC_2
Treatment delays	I'm working with a gentleman right now that just lost his job and lost his insurance and isn't wanting to apply for Medicaid. So he is now delaying his treatment until he starts a new job and has new insurance. I feel confident that we are able to work through the patients that we're aware of but it is concerning. I'm sure there's a lot more out there that we're not aware of that are delaying because of that reason. NCI_RUCC_1
Stopping Treatment	This treatment, it's a five hundred thousand dollar treatment, and you get four cycles of it at eight weeks apart. We had two patients, in the last couple months, cancel their fourth cycle due to financial reasons, and they were afraid their insurance wasn't going to pay more, but they didn't tell the nurse that. They just called and canceled, no one's following up on them. The doctor's like, "Yeah, that's okay." Then we find out afterwards, as finances, so no one contacted me and we would have rest assured them that there is help for co-pays. NCI_RUCC_1
Medication adherence	So, the patients, it's like 25% of the patients don't take their prescription meds as directed because they can't afford it. They may take it every other time to take it, or they may take it every other day or they might - because they can't afford the whole prescription and so, they come in and the doctor is like, "Are you taking it?" and they'll be like, "Well, no, I'm not," and we label them as non-compliant because they're not taking it but it's not because - it's because they can't afford it. We just don't understand what we put our patients through a lot of the time. COC_RUCC_5
Meeting basic needs	
Paying bills	I have had couples contemplate divorce in that they would be able to shelter half of their finances if they divorced and split 50-50 and the patient would then go file for bankruptcy due to their medical bill debt and the other spouse would have half of the finances and would not be responsible for the - potentially would not be responsible for the debt. That's kind of extreme. That's kind of like one extreme that I've seen. COC_RUCC_6
	Just the normal - and kind of like the everyday distress has just been like, "How am I going to pay for this?" Making choices about not being able to go on a trip or not getting a different car; making different choices on what they could spend. I've had patients having to make tough choices about food, so we've tried to give them assistance so that they can be sure to have healthy food. "I can't buy all those fresh fruits and vegetables that you're telling me to eat because I can't afford them," so we try to help them with that and just the stress with families. "Are we able to pay the bills? Can we pay the utilities? Can we pay the rent?" that kind of stuff. COC_RUCC_6
Employment/ patient and family	We haven't even talked about yet the effect of cancer treatment that goes on for a longer period of time when someone can be off of work and now, they lose their job. We haven't even talked about that. You lose your job, you lose your insurance, as well, so that's a lot of our - my two worst populations. COC_RUCC_5
	I have a mom right now, she lives in XX and so she's about three hours away. She's staying here and she lost her job. She's very sad about it, because she worked really hard to get to this place with her job. I think that she was just like I can't believe that this is the expectation for me to stay here for six months, and now when I go back home I'm going to have to find a new job. I'm going to have to work myself up and like I'm probably not going to get paid well. And then like if you try to explain that to the provider, the provider is like well, right. Yeah, that's right. That's what they need to do to keep their patient safe and healthy. COC_RUCC_2.

Theme & Sub-Themes	Representative Quote (Cancer Program Type, RUCC)
Housing	We had a guy who was in our [redacted city] office actually that ended up becoming homeless and he was … his new home was under a bridge, basically. Still showed up for treatment. We didn't find out until we were needing him to come back for something. We had no way to get a hold of him, he would just show up at his time. So that was kind of a dawning of discovery and looking that, you know, he looked a little more disheveled and those type of things. So that was one of our specific examples in our [redacted city] office, that's probably the most profound one that we've had. COC_RUCC_7

Abbreviations: COC=Commission on Cancer accredited, non-COC=non-Commission on Cancer accredited, RUCC=Rural-Urban Continuum Code)

Author Manuscript
Author Manuscript
Author Manuscript
Author Manuscript