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# How Cancer Programs Identify and Address the Financial Burdens of Rural Cancer Patients

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**Ethics Approval:** All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the Institutional Review Board at Oregon Health & Science University and determined exempt by the Institutional Review Boards at the University of North Carolina at Chapel Hill, University of Washington, University of Kentucky, University of Iowa, University of South Carolina, Case Western University.

**Consent to Participate:** This study was determined exempt by the Institutional Review Boards at the University of North Carolina at Chapel Hill, University of Washington, University of Kentucky, University of Iowa, University of South Carolina, Case Western University, and Oregon Health & Science University. All participants were given an information sheet detailing the purpose of the study, study contact information, their rights as research participants, that all data will be analyzed and presented in aggregate, and any identifying information will be removed from transcripts and quotes.

**Consent for Publication:** Prior to starting the interviews, all participants were given an information sheet and informed that all data will be analyzed and presented in aggregate, and any identifying information will be removed from transcripts and quotes used in publication.

**Code Availability:** N/A

## Abstract

**Purpose:** Financial toxicity is associated with negative patient outcomes and rural populations are disproportionately affected by the high costs of cancer care compared to urban populations. Our objective was to (1) understand cancer programs' perceptions of rural-urban differences in cancer patients' experiences of financial hardship, (2) evaluate the resources available to cancer patients across the rural-urban continuum, and (3) determine how rural and urban health care teams assess and address financial distress in cancer patients.

**Methods:** Seven research teams within the Cancer Prevention and Research Control Network conducted semi-structured interviews with cancer program staff who have a role in connecting cancer patients with financial assistance services in both rural and urban counties. Interviews were audio-recorded and transcribed. We identified themes using descriptive content and thematic analysis.

**Results:** We interviewed 35 staff across 29 cancer care programs in seven states, with roughly half of respondents from programs in rural counties. Participants identified differences in rural and urban patients' experiences of financial hardship related to distance required to travel for treatment, underinsurance, and low socioeconomic status. Insufficient staffing was an identified barrier to addressing rural and urban patients' financial concerns.

**Conclusions:** Improved financial navigation services could mitigate the effects of financial toxicity experienced by cancer patients, particularly rural patients, throughout treatment and survivorship. Future research is needed to improve how cancer programs assess financial hardship in patients and to expand financial navigation services to better serve rural cancer patients.

### Keywords

Cancer; Oncology; Rural; Financial Toxicity; Financial Assistance; Navigation

## Introduction

The financial burden of cancer care goes beyond the direct costs of treatment and includes expenses associated with transportation, housing, and other out-of-pocket costs [1]. This financial burden, often referred to as financial hardship or toxicity, is associated with negative patient outcomes, including increased anxiety, poor health-related quality of life, and cancer treatment non-adherence [2–5]. Rural populations are disproportionately affected by the high costs of care with 50.5% of rural cancer survivors reporting some level of financial hardship due to their diagnosis and treatment compared to 38.8% of urban cancer survivors [6]. Multiple factors may contribute to this disparity. Many rural residents are uninsured or under-insured or have less flexible work leave policies compared to urban residents [7.] Travel expenses are greater for rural residents who often need to drive longer distances to receive treatment [7]. Rural residents are also more likely to live in medically underserved areas and have less access to comprehensive support services to address the financial hardship of cancer diagnosis and treatment [7].

To address financial hardship, some cancer programs provide financial navigation services. Financial navigation is a proactive approach to help patients navigate and manage the complicated financial aspects of cancer resulting from both direct and indirect costs [8]. Financial navigators are distinct from general oncology navigators as they help patients understand insurance policies, out-of-pocket costs, and connect them to resources to help offset the costs of care to reduce or prevent financial hardship. Financial navigators have been shown to reduce financial hardship; however, financial navigation is still a relatively new service with few training programs available in the United States (U.S.) [9]. As a result, cancer program staff (e.g., case managers, nurse navigators, social workers) often take on the role of financial navigation in addition to their regular job responsibilities [10]. However, dedicated financial navigators may be critical for cancer patients financial needs to be adequately addressed. In prior research, oncology care navigators reported that patients receive inadequate financial support for drug copayments, insurance premiums, employment issues, and travel [11,12]. Research to date has not explored differences between experiences of staff or processes to assist patients with financial needs at rural and urban cancer programs. Less is known about financial assistance resources available that specifically target the needs of rural patients, regardless of the location of the cancer care program.

To better understand processes of assisting patients with financial needs, we interviewed staff from a purposeful sample of cancer programs across the rural-urban continuum in the U.S. to: (1) understand cancer programs' perceptions of rural-urban differences in cancer patients' experiences of financial hardship, (2) evaluate the resources available to cancer patients across the rural-urban continuum, and (3) determine how rural and urban health care teams assess and address financial hardship in cancer patients.

## Methods

This study was conducted by the Cancer Prevention and Control Research Network (CPCRN), a research network of eight universities across the U.S., funded by the Centers for Disease Control and Prevention. The mission of the CPCRN is to accelerate the adoption and implementation of evidence-based cancer prevention and control strategies, particularly for underserved populations [13]. The CPCRN rural cancer workgroup conducted semi-structured interviews with cancer program staff in seven CPCRN states (IA, KY, NC, OH, OR, SC, WA). This study was deemed exempt by the Institutional Review Boards at 6 CPCRN sites and was approved under expedited review at the seventh site (OR).

### Sample.

A purposeful sampling approach was used to attain representation across geography and cancer program type. Programs were categorized by rural-urban location as defined by the U.S. Department of Agriculture's 2013 Rural-Urban Continuum Codes (RUCC) [14]. RUCC categories for counties are based upon their population size and proximity to a metropolitan area. Three categories of rural/urban location were defined based on the RUCC of the county where each cancer program was located. One category designated urban cancer programs (RUCC=1–3) and two categories designated non-metro or rural programs (RUCC 4–6 and RUCC 7–9). We sampled cancer programs across the three categories to achieve equitable distribution across RUCCs and variation in rurality, with programs in the RUCC 7–9 category considered to be the most rural. Programs were also grouped by type to gain variation in program size, resources and infrastructure available: National Cancer Institute (NCI)-designated cancer center, Commission on Cancer (CoC)-accredited, non-CoC accredited hospital, or free-standing cancer clinic. Each CPCRN site aimed to recruit participants from 4 programs, with maximum variation across RUCC and program-type categories; however, we prioritized recruiting a participant from each RUCC group since the purpose of the study was to understand differences between rural and urban cancer programs.

Within each program we recruited staff whose job involved connecting cancer patients to financial assistance resources. Potential study participants were identified using professional networks and outreach to eligible cancer programs. We anticipated that the job titles of staff across programs would be variable; therefore, to identify potential participants, we asked questions such as “Can you connect me to the department or individual responsible for financial counseling or navigation for cancer patients?” Individuals interested in participating were provided a study information sheet and a phone or in-person interview was scheduled. At sites where the study was deemed exempt by IRB, prior to the interview, study staff reviewed the purpose of the study, individual’s rights as research subjects, and contact information for the study coordinator. At the remaining site (OR), interviewers obtained verbal informed consent from each participant prior to the interview.

### Semi-structured Interview Guide.

We developed a semi-structured interview guide and demographic survey, which was piloted with cancer program staff members (n=3). The same interview guide was used with all participants and asked them to describe the financial resources available to cancer patients in general, resources specifically for rural patients, how patients are screened for financial hardship, and their perceptions of rural-urban differences in financial hardship (Appendix A).

Trained interviewers from each CPRCN site conducted the interviews between December 2018 and June 2019. The interviewer used the demographic survey to collect information about the participant (e.g., demographics and training) and cancer program (e.g., cancer program type and treatment services provided). Interviews typically lasted 30 to 90 minutes.

### Data Analysis.

Interview recordings were transcribed verbatim and all data de-identified. Frequencies and percentages for program and participant characteristics were calculated from survey data. Interview transcripts were analyzed using content and thematic analysis methods using Dedoose [15–17]. We developed a codebook based on the research questions and refined it by independently coding two transcripts and revising definitions and decision rules. The final codebook was applied to the remaining interview transcripts. Transcripts were independently coded by two research team members (RT, MV). Once the coded transcripts were reconciled, code reports were generated for each code and narrative summaries were written. Findings were verified by members of the CPCRN workgroup and checked for consistency and reliability [17].

## Results

### Interview Site and Participant Characteristics.

Thirty-five interviews were conducted across 29 cancer programs in seven states. Program characteristics are detailed in Table 1. Among these cancer programs, six sites (21%) were NCI-designated cancer centers, and nearly half (45%) were non-NCI designated, CoC-accredited facilities. Less than half of the programs were in an urban county (45%), with 34% in a RUCC 4–6 county and 17% in a RUCC 7–9 county. Roughly three-fourths (76%) of programs had at least one financial counselor, and approximately one-fifth (21%) of programs had social workers who also provided additional financial support for cancer care.

Participant characteristics are detailed in Table 2. Thirty-seven percent had training in social work, 46% had a master's degree or higher, and 49% received training specific to their role from their formal education. The majority of participants who provided their job title were social workers (20%) and navigators (17%). Two participants, both from rural cancer programs, had two job titles.

### Staff Perceptions of Rural-Urban Differences in Patient Experiences of Financial Hardship and Access to Financial Assistance Resources.

Participants identified two overarching areas of rural-urban differences in patients' experiences of financial hardship (see Table 3). First, although participants identified commonalities in experiences of financial hardship in both rural and urban cancer patients, they also identified several that were distinct to rural patients. Second, participants reported that rural patients had access to fewer cancer care resources (for both clinical care and financial support) compared to patients in urban and identified the multilevel barriers rural patients faced when attempting to access available resources to manage financial hardship (Figure 1).

**Rural patients' experiences of financial hardship.—**Participants from rural and urban cancer programs perceived that rural patients experience financial hardship due to greater socioeconomic disadvantage in rural areas, that created difficulty managing out-of-pocket costs. Additionally, participants from rural centers frequently described the majority of their patient populations as Medicare beneficiaries with fixed incomes, which caused difficulty managing out-of-pocket costs for their care. Rural cancer patients faced high transportation costs since they traveled longer distances to receive the same level of clinical care as urban patients and had limited or no access to public or private transportation. Participants, particularly those from urban cancer programs, shared that it was sometimes necessary for rural patients to locate temporary lodging close to the hospital/cancer program during their treatment, another out-of-pocket expense typically not covered by insurance or another resource.

However, a few participants from urban cancer programs reported seeing no differences in experiences of financial hardship between rural and urban patients. Rather, these participants perceived that issues of low or fixed income, or un- and underinsurance led to of financial hardship and they believed these socioeconomic concerns to be endemic in both rural and urban populations.

**System and institutional-level challenges accessing resources.—**Participants commonly discussed system and institutional-level barriers that rural patients faced in the process of obtaining financial assistance. Participants noted that the complex and cumbersome nature of applying for financial assistance resources was a challenge for rural patients. Participants discussed how long approval processes for services cause undue financial strain and stress for patients. The complexity of insurance systems meant that sometimes patients were unaware of available programs, such as Medicare savings programs. While these problems were also mentioned as barriers that urban patients faced, participants discussed how these issues were more acutely experienced by rural patients because of fewer staff in rural programs dedicated to helping patients navigate financial assistance. Lack of access to the internet or limited cell-phone reception meant that rural patients could not use web-based applications or be easily reached by the health care team.

Overwhelmingly, the most common barrier mentioned by participants was the problematic nature of insurance coverage eligibility and how insurance status affected the resources patients were eligible to receive. Many rural patients they encountered could not afford private health insurance but were not qualified for Medicaid [18]. They also described how rural, Medicare-insured patients could still accumulate out-of-pocket costs (e.g. coinsurance, indirect costs), resulting in substantial financial burden [19]. These Medicare patients would often not qualify for additional services to help pay those costs, such as transportation services, leaving them with no affordable options for transportation.

Participants reported that in general there were fewer financial assistance resources available in rural areas, particularly at the county-level. For example, although rural cancer programs served patients from multiple surrounding counties, community-based resources (through churches or local non-profits) within the county of the cancer program were not available to patients from other counties. Participants also discussed that resources for rural patients were difficult to maintain because of inconsistent demand or funding; thus, resulting in inefficient or ineffective services. For example, transportation services utilized by patients from rural areas would be shared among multiple rural patients and sometimes run late, causing delays that interfered with care. Volunteer transportation and ride-sharing programs were also difficult for rural patients to use because of the inflexibility of transportation options or lack of availability in rural areas, despite reimbursement partnerships with larger health care systems.

**Patient-level challenges accessing resources.—**Participants from urban and rural programs frequently reported that rural patients were less likely to be forthcoming about their financial difficulties. Other patient-level factors that were perceived to effect rural patients' ability to access financial assistance resources included low health literacy and cultural or language barriers, which also compounded system-level barriers such as navigating insurance systems or assistance programs.

### Internal and External Resources Available to Patients across the Rural-Urban Continuum.

Participants discussed numerous resources, programs, and personnel within their cancer programs devoted to assisting patients with financial concerns. Across the rural-urban continuum, participants noted that knowledge of resources available to cancer patients (particularly to assist with non-medical expenses), was acquired informally and such institutional knowledge was often lost with staff turnover.

**Internal Resources.—**Examples of internal resources across cancer programs included hospital foundations or charity care, payment programs, referral services to external organizations, financial specialist staff, transportation assistance, and grocery vouchers. Participants from urban programs more often mentioned internal resources aimed at assisting patients in finding temporary housing during treatment, connecting patients to cancer support groups for emotional or social support, and helping patients complete financial assistance applications.

**External Resources.—**Participants also discussed external resources they were aware of outside their cancer program. External resources described by participants across the rural-urban continuum included the American Cancer Society, transportation services, pharmaceutical assistance programs, foundations (public/private, local/state/national), local agencies, community-based cancer associations, outreach services, and support groups. Compared to their rural counterparts, participants from urban cancer programs more often mentioned connecting patients with resources through national societies and organizations (e.g., Leukemia and Lymphoma Society) and external resources to assist with non-medical costs such as utility bills, rent or mortgage payments, food, and gas. Participants from rural cancer programs more frequently mentioned utilizing financial assistance programs through churches, pharmaceutical patient assistance programs, and the Department of Social Services.

### How Care Teams Assess and Address Financial Hardship.

All participants interviewed were part of the process of assessing and addressing financial hardship for cancer patients. These processes were largely similar between rural and urban cancer programs. Many participants explained they were a primary point of contact to assess and connect patients to services or other members of the care team that could help alleviate financial hardship. The primary difference between rural and urban cancer programs was the lack of navigators in rural programs whose position primarily focused on helping patients manage the financial aspects of their care. As a result, some participants from rural cancer programs described their role as varying day-to-day depending on their workload and the financial-related challenges presented by patients. Across rural and urban programs, participants described the process of assisting patients with financial needs as including identifying financial concerns, connecting patients with resources, providing emotional support and advocacy.

Participants identified patient financial concerns in myriad ways (see Table 4). In general, the first steps were to meet with new patients, determine their insurance status and calculate out-of-pocket expenses to decide what financial assistance a patient might need. Participants from both rural and urban cancer programs mentioned using the National Comprehensive Cancer Network (NCCN) Distress Thermometer or other brief tools to detect patients with financial or social needs, but many commented they did not perceive these tools to be comprehensive assessments of financial need [20]. Patient financial hardship could also be detected by providers or other staff who would then refer patients to the appropriate person or resources to assist them. Despite the relatively universal use of screening, participants from rural cancer programs frequently described becoming aware of a patient's financial hardship during the course of their treatment rather than through an initial assessment.

Most rural participants perceived that few, if any, patients with financial hardship were overlooked, which they attributed to the smaller size of their cancer program. Participants from urban programs often reported that they believed there were many patients whose needs were not met and that patients who may need financial assistance were not detected due to time constraints on cancer program staff or because patients were not aware that financial assistance services were available. Staffing limitations were mentioned as a reason if patients were not screened for financial hardship or patient concerns not adequately addressed at both rural and urban programs.

## Discussion

Rural cancer patients are at increased risk for experiencing financial hardship and have greater difficulty accessing resources to address financial hardship. As cancer costs continue to rise it is important to optimize how both rural and urban cancer programs assess and address financial hardship. In our study, staff from a diverse group of cancer programs and geographic locations identified factors that impact rural cancer patients' experiences of financial hardship, barriers to accessing financial assistance and discussed their current practices for addressing financial concerns.

Participants in our study reported greater financial hardship in rural cancer patients due to substantial travel burdens and compounding socioeconomic disadvantage. Roughly 25% of rural residents live more than one hour away from the nearest medical or radiation oncologist and patients who live further from oncology providers are more likely to have worse cancer outcomes [21]. Even though restrictions on some transportation services by insurance type effect both rural and urban patients, the uneven distribution of oncology providers creates additional burden on already socioeconomically disadvantaged rural patients. Other structural factors may also impede a rural patient's ability to spend time commuting long distances (e.g., lack of sick leave) [7,22]. Efforts to bolster funding and support of transportation resources may help improve their capacity to meet the needs of rural patients.

Although rural patients may qualify for or utilize the same resources as urban patients, they may have greater difficulty accessing those resources. Poor internet and cell phone service was regularly mentioned as a barrier to accessing information and applications for assistance. Roughly 26.4% of rural areas in the U.S. do not have access to broadband and rural residents are less likely to use the internet to manage their personal health information [32–35]. Web-based options and mobile technologies may improve access to financial assistance resources for some patients but may worsen rural inequities without expanded broadband access or the availability of alternative modalities to access resources.

Across rural and urban cancer programs, brief tools or methods (most commonly the NCCN Distress Thermometer and insurance status) were used to assess or flag patients with financial needs. Such methods are not comprehensive, and many rural patients were perceived to not be forthcoming about financial concerns, likely limiting the effectiveness of those tools [20,23–25]. Comprehensive financial screening includes assessment of material burden, psychosocial distress, and behavioral responses to high costs care [25]. Universal, comprehensive screening prior to and throughout treatment, using measures such as the COST tool, may be beneficial to promptly address the financial needs of rural patients [26,27].

Additional financial navigation staff or dedicated training in financial navigation may help proactively address patients’ financial needs, particularly in rural cancer programs [28]. Such positions could be shared across cancer programs, or accessible via telehealth. Patient navigation can improve cancer screening and treatment outcomes; however, general cancer navigation services address far more than patient financial hardship, and patients stand to benefit from directed financial navigation services [10,12,29–31,28]. Formal financial navigation may also help standardize knowledge about available resources and improve dissemination about changes to federal, state, and local financial assistance. Noteably, urban cancer program staff reported limitations in their capacity to meet demand for financial assistance, suggesting that efforts to bolster financial navigation services should be implemented across rural and urban settings.

Finally, insurance and policy interventions may also benefit rural cancer patients struggling with financial hardship. Rural patients covered by Medicare, that do not meet the income requirements to qualify for additional Medicaid coverage, are often left with high out-of-pocket costs and navigating the options available to manage those additional costs is complex. Policy interventions such as Medicaid expansion or simplifying and expanding accessibility of Medigap policies may help lower cancer cost burdens for rural patients.

Although urban programs may generally have more resources available for patients to alleviate financial hardship, the barriers that rural cancer patients face were primarily reflective of structural barriers. This includes criteria to qualify for resources or the resource intensive nature of implementing, funding, and maintaining services to support rural patients (e.g., transportation or broadband internet access) that may not be simply addressed by referring more rural patients to urban programs. Therefore, bolstering financial hardship screening and resources in both rural and urban settings would benefit both patients and cancer programs to improve cancer care delivery.

### Limitations and Strengths.

We interviewed cancer program staff about their perceptions of patient financial hardship rather than interviewing patients themselves. However, the in-depth conversations with cancer care program staff provided insight into system-level barriers that may not be perceptible at the patient-level. Another potential limitation is that rural staff were asked about their perceptions of rural/urban differences in patient experiences of financial hardship and resource availability, but these rural programs likely treat few urban patients. However, we did so recognizing that rural staff commonly refer patients to urban-based cancer programs, have colleagues in urban programs, and/or have worked in urban settings themselves; therefore, they likely understand the differences in resource availability between rural and urban cancer programs even if they do not regularly have contact with urban-residing patients. There is a risk of selection bias in this study as we may not have been able to recruit participants from cancer programs without staff to address financial hardship. Therefore, the facilities represented in our study may be better positioned to address patient financial concerns. While each CPCRN site used its own interviewers, to minimize variability in how interviews were conducted, all interviewers were trained through UNC CHAI Core. Strengths of this study are the inclusion of sites from across seven geographically dispersed states and large representation of rural cancer programs.

### Conclusions.

Cancer programs play a crucial role in connecting patients with assistance to alleviate financial hardship associated with cancer care. However, rural patients may be less likely to have financial needs proactively addressed. Consistent with prior studies, cancer program staff perceive financial assistance resources for cancer patients to be lacking in general and especially challenging for rural patients to access [10]. This study provides recommendations for improving how cancer care programs address financial hardship, particularly among rural patients. This includes comprehensive screening, maintaining directories of financial resources available to patients, and increasing the number of trained staff members, such as financial navigators, dedicated to addressing financial hardship.

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## Availability of Data and Material:

Data available on request due to privacy/ethical restrictions.

## Appendix A. Semi-Structured Interview Guide

The development of the interview guide was informed by reviews of the literature and workgroup members' clinical and research expertise in cancer-related financial hardship.

CPCRN Rural Cancer Workgroup Interview Guide

Version 9.22.18

## REQUIRED QUESTIONS

With all questions, allow time for participant to answer open-endedly before probing.

### I. Overview of Organization and Role

**1.** Tell me a little bit about [*name of hospital / health system /clinic*] and your role here.

[*Prompts*]

- Where and how is cancer care provided (i.e., are there satellite sites/ locations)?
- How long have you worked here – and in what roles (build off response from survey when possible)?
- In general, what do your day-to-day job responsibilities look like?

**2.** What (if any) role do you have in assisting patients and families who are concerned about the cost of their cancer care?

[Associated costs may include direct medical expenses like co-pays/co-insurance/deductibles and medication costs, as well as non-medical expenses like transportation, housing, childcare, eldercare, and loss of employment.]

### II. Patient Experiences and Financial Resources

**3.** How do you know if your patients have financial concerns?

[Prompts]

- Who typically brings it up in conversation (e.g., patient, family member, you, health care provider, another team member)?
- To what extent, if any, have patients expressed frustration or concern with their providers not discussing financial issues during their treatment?

**4.** In your experience, how does cancer-related financial distress affect patients? Please share any specific patient examples.

[These are responses that you might hear from the respondents and may be potentially used as prompts to get the respondent started in conversation, i.e., for example…]

- Patients are less adherent to medication(s)
- Patients miss appointments or delay treatment
- Patients decline recommended care
- Patients have more emotional distress

- I don’t know / I don’t notice any effect(s)
- Patients and their families have lower quality of life

5. **Within your organization**, what structures/resources/personnel are in place to help patients and their families when they may have concerns about the costs of cancer care?

   *[Prompts*]

   - Medication assistance
   - Financial counseling
   - Transportation, housing, etc.
   - Charity care
   - Assistance applying for Medicaid / other insurance programs
   - Payment plan
   - Discounted rate for services

6. **Outside of your organization**, what resources, both formal and informal, are you aware of and would recommend to patients with financial concerns?

   *[Prompts*]

   - Community programs (please specify, explain)
   - Support group / advocacy organization
   - Resources from the American Cancer Society or other non-profit organizations
   - Prescription Drug Company Discounts/Grants

7. How do you communicate with members of the care team when patients have financial difficulties related to their cancer treatment?

   [*Prompts*]

   - Discuss during case conferences/tumor boards
   - Individual discussions with pharmacy staff, physicians, nurses, etc.
   - During rounds with the care team
   - Notation in EMR
   - Phone or email communication with care team members

## III. Differences between Rural and Urban Cancer Patients

8. What, if any, financial burden differences have you noticed between patients from rural areas and those from urban areas?

**9.** What specific programs/resources, if any, are available to patients who live in rural areas and/or must travel long distances to your hospital/clinic?

**10.** What obstacles / challenges do rural-residing patients experience in trying to access these resources?

[These are responses that you might hear from the respondents and may be potentially used as prompts to get the respondent started in conversation, i.e., for example…]

- Language
- Literacy
- Application process too complex
- Patients do not discuss financial concerns with provider
- Patients do not know what resources exist
- Patients do not qualify for existing resources
- Personnel do not have enough time to address financial needs
- Personnel lack knowledge about resources

**11.** What gaps do you see in existing resources available to rural cancer patients?

### VI. Conclusion

**12.** What suggestions do you have for improving the process of addressing cancer patients’ financial barriers to cancer care?

**13.** What do you consider to be the most immediate need and area for intervening in your community? (i.e., intervention topics)

**14.** Is there anyone else within [*name of hospital, clinic, health system*] that you feel we should talk to about the topics we covered today? [*If yes, please obtain their name and contact information.]*

## References

1. PDQ Adult Treatment Editorial Board. Financial Toxicity and Cancer Treatment. Bethesda, MD: National Cancer Institute. https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq. Accessed 01/20/2020
2. 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. doi:10.1200/jco.2015.63.2232 [PubMed: 26926678]
3. Nipp RD, Zullig LL, Samsa G, Peppercorn JM, Schrag D, Taylor DH Jr., Abernethy AP, Zafar SY (2016) Identifying cancer patients who alter care or lifestyle due to treatment-related financial distress. Psychooncology 25 (6):719–725. doi:10.1002/pon.3911 [PubMed: 26149817]
4. Zafar SY, Peppercorn JM, Schrag D, Taylor DH, Goetzinger AM, Zhong X, 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. doi:10.1634/theoncologist.2012-0279 [PubMed: 23442307]

5. Kent EE, Forsythe LP, Yabroff KR, Weaver KE, de Moor JS, Rodriguez JL, Rowland JH (2013) Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? Cancer 119 (20):3710–3717. doi:10.1002/cncr.28262 [PubMed: 23907958]
6. Zahnd WE, Davis MM, Rotter JS, Vanderpool RC, Perry CK, Shannon J, Ko LK, Wheeler SB, Odahowski CL, Farris PE, Eberth JM (2019) Rural-urban differences in financial burden among cancer survivors: an analysis of a nationally representative survey. Support Care in Cancer. doi:10.1007/s00520-019-04742-z
7. Charlton M, Schlichting J, Chioreso C, Ward M, Vikas P (2015) Challenges of Rural Cancer Care in the United States. Oncology. 29 (9):633–640 [PubMed: 26384798]
8. Sherman D, Fessele K (2019) Financial support models: a case for use of financial navigators in the oncology setting. Clin J Oncol Nurs 23 (5):14–18. doi:10.1188/19.Cjon.S2.14-18 [PubMed: 31538990]
9. Yezefski T, Steelquist J, Watabayashi K, Sherman D, Shankaran V (2018) Impact of trained oncology financial navigators on patient out-of-pocket spending. Am J Manag Care 24 (5 Suppl):S74–s79 [PubMed: 29620814]
10. 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 in Cancer 26 (4):1315–1321. doi:10.1007/s00520-017-3958-3
11. Bregar AJ, Alejandro Rauh-Hain J, Spencer R, Clemmer JT, Schorge JO, Rice LW, Del Carmen MG (2017) Disparities in receipt of care for high-grade endometrial cancer: A National Cancer Data Base analysis. Gynecol Oncol 145 (1):114–121. doi:10.1016/j.ygyno.2017.01.024 [PubMed: 28159409]
12. Vanderpool RC, Nichols H, Hoffler EF, Swanberg JE (2017) Cancer and Employment Issues: Perspectives from Cancer Patient Navigators. J of Cancer Educ 32 (3):460–466. doi:10.1007/s13187-015-0956-3 [PubMed: 26627904]
13. Cancer Prevention and Control Research Network. CPCRN: Cancer Prevention and Control Research Network. https://cpcrn.org/. Accessed 01/20/2019
14. US Department of Agriculture. Rural-Urban Continuum Codes. https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/. Accessed 01/20/2019
15. Dedoose (2018). 8.0.35 edn. SocioCultural Research Consultants, LLC, Los Angeles, CA
16. Hsieh HF, Shannon SE (2005) Three approaches to qualitative content analysis. Qual Health Res 15 (9). doi:10.1177/1049732305276687
17. Creswell JW, Poth CN (2018) Qualitative Inquiry and Research Design: Choosing Among Five Approaches. 4 edn. SAGE Publications, Inc., USA
18. US Centers for Medicare and Medicaid Services (2020) Eligibility. Medicaid.gov. https://www.medicare.gov/your-medicare-costs/medicare-costs-at-a-glance. Accessed May 13, 2020
19. US Centers for Medicare and Medicaid Services (2020) Medicare costs at a glance. https://www.medicare.gov/your-medicare-costs/medicare-costs-at-a-glance. Accessed 5/13/2020
20. National Comprehensive Cancer Network (2020) NCCN Distress Thermometer and Problem List for Patients.
21. Hung P, Deng S, Zahnd WE, Adams SA, Olatosi B, Crouch EL, Eberth JM (2020) Geographic disparities in residential proximity to colorectal and cervical cancer care providers. Cancer 126 (5):1068–1076. doi:10.1002/cncr.32594 [PubMed: 31702829]
22. Lin CC, Bruinooge SS, Kirkwood MK, Olsen C, Jemal A, Bajorin D, Giordano SH, Goldstein M, Guadagnolo BA, Kosty M, Hopkins S, Yu JB, Arnone A, Hanley A, Stevens S, Hershman DL (2015) Association Between Geographic Access to Cancer Care, Insurance, and Receipt of Chemotherapy: Geographic Distribution of Oncologists and Travel Distance. J Clin Oncol 33 (28):3177–3185. doi:10.1200/jco.2015.61.1558 [PubMed: 26304878]
23. Jacobsen PB, Wagner LI (2012) A new quality standard: the integration of psychosocial care into routine cancer care. J Clin Oncol 30 (11):1154–1159. doi:10.1200/jco.2011.39.5046 [PubMed: 22412134]
24. 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). doi:10.1093/jnci/djw205

25. Tucker-Seeley RD, Thorpe RJ (2019) Material-Psychosocial-Behavioral Aspects of Financial Hardship: A Conceptual Model for Cancer Prevention. Gerontologist 59 (Suppl 1):S88–s93. doi:10.1093/geront/gnz033 [PubMed: 31100144]
26. Khera N, Holland JC, Griffin JM (2017) Setting the stage for universal financial distress screening in routine cancer care. Cancer 123 (21):4092–4096. doi:10.1002/cncr.30940 [PubMed: 28817185]
27. de Souza JA, Yap BJ, Wroblewski K, Blinder V, Araújo FS, Hlubocky FJ, Nicholas LH, O’Connor JM, Brockstein B, Ratain MJ, Daugherty CK, Cella D (2017) Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). Cancer 123 (3):476–484. doi:10.1002/cncr.30369 [PubMed: 27716900]
28. 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. J Oncol Pract 14 (2):e122–e129. doi:10.1200/jop.2017.024927 [PubMed: 29272200]
29. Palomino H, Peacher D, Ko E, Woodruff SI, Watson M (2017) Barriers and Challenges of Cancer Patients and Their Experience with Patient Navigators in the Rural US/Mexico Border Region. J Cancer Educ 32 (1):112–118. doi:10.1007/s13187-015-0906-0 [PubMed: 26362872]
30. Petereit D, Omidpanah A, Boylan A, Kussman P, Baldwin D, Banik D, Minton M, Eastmo E, Clemments P, Guadagnolo BA (2016) A Multi-faceted Approach to Improving Breast Cancer Outcomes in a Rural Population, and the Potential Impact of Patient Navigation. S D Med 69 (6):268–273 [PubMed: 27443111]
31. Torres E, Richman AR, Schreier AM, Vohra N, Verbanac K (2019) An Evaluation of a Rural Community-Based Breast Education and Navigation Program: Highlights and Lessons Learned. J Cancer Educ 34 (2):277–284. doi:10.1007/s13187-017-1298-0 [PubMed: 29150748]
32. Duggan M, Smith A (2013) Cell internet use 2013. Pew ResearchCenter, Washington, DC https://www.pewresearch.org/internet/2013/09/16/cell-internet-use-2013/. Accessed September 1, 2020.
33. Anderson M (2015) https://www.pewresearch.org/internet/2015/10/29/the-demographics-of-device-ownership/. Accessed September 1, 2020.
34. Greenberg-Worisek AJ, Kurani S, Finney Rutten LJ, Blake KD, Moser RP, Hesse BW (2019) Tracking Healthy People 2020 Internet, Broadband, and Mobile Device Access Goals: An Update Using Data From the Health Information National Trends Survey. J Med Internet Res 21 (6):e13300. doi:10.2196/13300 [PubMed: 31237238]
35. Federal Communications Commission (2019) 2019 Broadband Deployment Report. Washington, D.C. https://docs.fcc.gov/public/attachments/FCC-19-44A1.pdf. Accessed September 8, 2020.

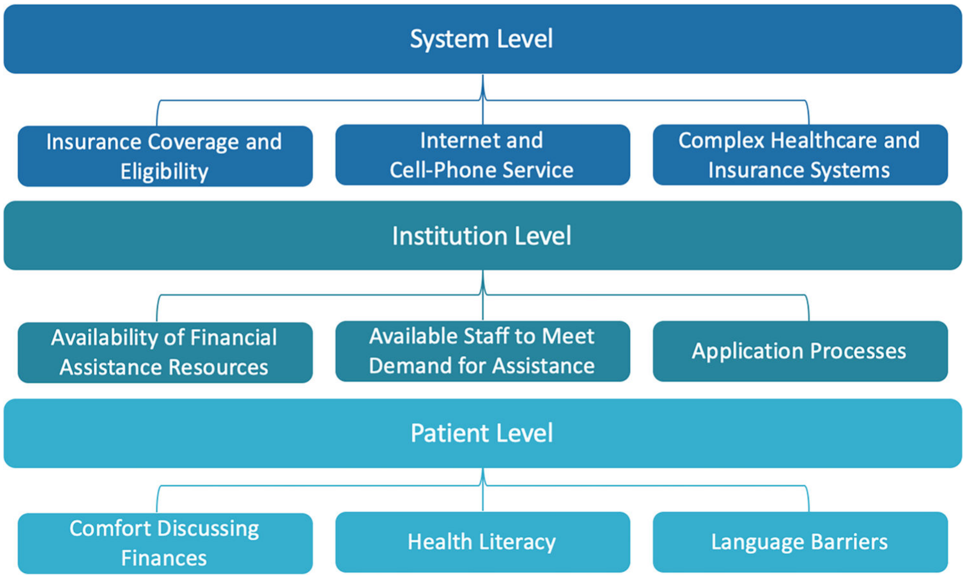

**Figure 1. Multilevel Barriers to Accessing Financial Assistance Resources for Rural Patients**

This figure shows the different barriers mentioned by participants to accessing financial assistance resources at the system, institution, and patient levels.

## Table 1:

Cancer Program Characteristics

| | All | Urban | Rural |
|---|---|---|---|
| | N (%) (n=29) | N (%) (n=13) | N (%) (n=15) |
| Cancer Center Type[a] | | | |
| NCI-designated | 6 (21%) | 6 (46%) | 0 (0%) |
| Non-NCI designated, CoC-accredited | 13 (45%) | 6 (46 %) | 7 (47%) |
| Non-CoC-accredited | 8 (28%) | 0 (0%) | 8 (53%) |
| Free Standing | 2 (7%) | 1 (8 %) | 0 (0%) |
| Rural-Urban Continuum Code (RUCC) of Site Location[b] | | | |
| RUCC 1–3 (urban) | 13 (45%) | | |
| RUCC 4–6 (non-metro/rural) | 10 (34%) | | |
| RUCC 7–9 (non-metro/rural) | 5 (17%) | | |
| Multiple[c] | 1 (3%) | | |
| NCORP Site, Yes | 11 (38%) | 7 (54%) | 4 (27%) |
| Catchment Area Size | | | |
| Single County | 6 (21%) | 1 (8%) | 5 (33%) |
| Multiple Counties | 19 (66%) | 8 (62%) | 10 (67%) |
| Entire State/Multiple States | 4 (14%) | 4 (30%) | 0 (0%) |
| Treatment Services Provided[d] | | | |
| Blood and/or Marrow Transplant | 11 (38%) | 7 (54%) | 4 (27%) |
| Chemotherapy (Infusion) | 29 (100%) | 13 (100%) | 15 (100%) |
| Chemotherapy (Oral) | 28 (97%) | 12 (92%) | 15 (100%) |
| Clinical Trials | 16 (55%) | 10 (77%) | 6 (40%) |
| Immunotherapy | 24 (83%) | 12 (92%) | 12 (80%) |
| Psycho-oncology Services | 14 (48%) | 10 (77%) | 4 (27%) |
| Radiation Oncology | 23 (79%) | 13 (100%) | 10 (67%) |
| Supportive Treatments (Complementary/Palliative Services) | 19 (66%) | 12 (92%) | 7 (47%) |
| Surgical Oncology | 21 (72%) | 11 (85%) | 10 (67%) |
| Number of Financial Counselors at Cancer Program | | | |
| 0 | 7 (24%) | 2 (15%) | 5 (31%) |
| 1–3 | 17 (59%) | 7 (54%) | 9 (60%) |
| 4+ | 5 (17%) | 4 (8%) | 1 (7%) |
| Additional services/staff that address financial assistance for cancer care[d] | | | |
| Social Workers | 6 (21%) | 6 (46%) | 0 (0%) |
| Nurses (Navigators, Case Manager) | 5 (17%) | 4 (31%) | 0 (0%) |
| Other Navigation/Counseling | 8 (28%) | 8 (62%) | 0 (0%) |

| | All | Urban | Rural |
|---|---|---|---|
| | **N (%) (n=29)** | **N (%) (n=13)** | **N (%) (n=15)** |
| Pharmacists | 2 (7%) | 0 (0%) | 2 (13%) |
| Billing or Other Office Support | 4 (14%) | 0 (0%) | 3 (20%) |
| Internal Programming | 12 (41%) | 4 (31%) | 8 (53%) |
| External Programming | 3 (10%) | 1(7%) | 2 (13%) |

[a] Non-NCI CoC accredited programs include those cancer programs that have received accreditation from the Commission on Cancer but are not NCI-Designated Comprehensive Cancer Centers or NCI-Designated Network Cancer Programs. This category includes programs such as Comprehensive Community Cancer Programs, Integrated Network Cancer Programs, etc. https://www.facs.org/quality-programs/cancer/coc/accreditation/categories

[b] The U.S. Department of Agriculture Economic Research Service 2013 rural-urban continuum codes scheme categorizes metropolitan counties by the population size of their metropolitan area and nonmetropolitan counties by degree of urbanization and adjacency to a metropolitan area. (https://www.ers.usda.gov/data-products/rural-urban-continuum-codes

[c] One participant worked in a rural free-standing clinic that was part of a organization that had clinics in multiple different counties of different RUCCs. This individuals was not included in either the rural or urban columns.

[d] Indicates a question in which multiple answers could be provided (i.e., columns may exceed 100%)

## Table 2:

Participant Characteristics

| | All | Urban | Rural |
|---|---|---|---|
| | N (%) (n=35) | N (%) (n=18) | N (%) (n=16) |
| Age | | | |
| <40 | 9 (26%) | 4 (22%) | 5 (31%) |
| 40–49 | 16 (46%) | 9 (50%) | 7 (47%) |
| 50–59 | 4 (11%) | 3 (17%) | 1 (6%) |
| 60+ | 5 (14%) | 1 (6%) | 3 (19%) |
| Not Provided | 1 (3%) | 1 (6%) | 0 (0%) |
| Female, Yes | 31 (89%) | 16 (89%) | 14 (88%) |
| Hispanic ethnicity, Yes | 1 (3%) | 1 (6%) | 0 (0%) |
| Race | | | |
| White | 31 (89%) | 16 (89%) | 14 (88%) |
| Black | 3 (8%) | 1 (6%) | 2 (12%) |
| Other | 1 (3%) | 1 (6%) | 0 (0%) |
| Discipline of Training | | | |
| Social Work | 13 (37%) | 9 (50%) | 3 (19%) |
| Nursing | 5 (14%) | 0 (0%) | 5 (31%) |
| Finance/Business | 6 (17%) | 4 (22%) | 2 (12%) |
| Other (Public Health, Pharmacy, etc.) | 12 (34%) | 4 (22%) | 8 (50%) |
| Highest Degree Obtained | | | |
| Some College/Associate Degree | 7 (20%) | 5 (28%) | 2 (12%) |
| Bachelor’s Degree | 12 (34%) | 3 (17%) | 9 (53%) |
| Master’s Degree or Higher | 16 (46%) | 10 (56%) | 5 (31%) |
| Number of Years Working at Current Site | | | |
| 1–2 Years | 6 (17%) | 3 (17%) | 3 (18%) |
| 3–4 Years | 7 (20%) | 4 (22%) | 3 (18%) |
| 5–6 Years | 5 (14%) | 4 (22%) | 1 (6%) |
| 7–10 Years | 7 (20%) | 3 (17%) | 3 (19%) |
| 10+ Years | 10 (29%) | 4 (22%) | 6 (38%) |
| Type of Training Received for Role[b] | | | |
| Training from Formal Degree | 17 (49%) | 7 (39%) | 9 (56%) |
| Training from Accredited Program | 10 (29%) | 8 (44%) | 1 (6%) |
| On the Job Training | 6 (17%) | 4 (22%) | 1 (6%) |
| Self-Study | 11 (31%) | 4 (22%) | 6 (37%) |
| No Specific Training | 5 (14%) | 2 (11%) | 3 (19%) |

| | **All** | **Urban** | **Rural** |
|---|---|---|---|
| | **N (%) (n=35)** | **N (%) (n=18)** | **N (%) (n=16)** |
| Other | 16 (46%) | 6 (33%) | 10 (63%) |
| Job Title [a] | | | |
| Care Coordinator | 2 (6%) | 0 (0%) | 2 (12%) |
| Clinical Director | 2 (6%) | 0 (0%) | 2 (12%) |
| Education and Resource Director | 1 (3%) | 0 (0%) | 1 (6%) |
| Financial Counselor | 4 (11%) | 1 (6%) | 3 (19%) |
| Social Worker | 7 (20%) | 4 (22%) | 3 (19%) |
| Hospital Financial Administration | 3 (9%) | 0 (0%) | 3 (19%) |
| Navigator | 6 (17%) | 2 (11%) | 3 (19%) |
| Program Manager/Research Coordinator | 2 (6%) | 1 (6%) | 1 (6%) |
| Not Provided | 10 (29%) | 7 (39%) | 3 (19%) |

[a] Indicates the question could have multiple responses (i.e., column totals may exceed 100%

[b] Two participants held multiple job titles

Note: One participant worked at a free-standing clinic that served multiple RUCCs. They were not included in either the rural or urban column.

## Table 3.

Staff’s Perceptions of Rural-Urban Differences in Patients’ Experiences of Financial Hardship

| **Theme, *Subtheme*** | **Representative Quote (Cancer Program Type, Rural/Urban)** |
|---|---|
| **Theme: Rural patients’ experiences of financial hardship** | |
| *Greater socioeconomic disadvantage in rural areas* | “Like I said, this is a pretty poor community. Jobs are slim pickings. We see a lot of elderly people that are on disability or Social Security so the money is just not there for them..” (FSC[a], Rural) |
| *Transportation and lodging costs* | “People are coming an hour, an hour-and-15 minutes, to get to the closest treatment facility, which is here. And if you start thinking about what that looks like when you have radiation every day, just for 15 minutes, but for 6 weeks, 5 days a week, trying to get here, and that’s, you know, an hour-and-a-half to get here, an hour-and-a-half back, and then a 15-minute appointment still takes up the whole day. And just, like I said, if the ends are barely meeting before, then you add in that much gas cost and that can make things very difficult.” (COC[b], Urban) |
| *No differences between rural and urban patients* | “It’s transportation. Even here in [urban county] it’s transportation or employment, their job situation.” (NCI[c], Urban) |
| **Theme: Challenges accessing resources** | |
| System and Institutional-Level | |
| *Cumbersome application processes* | “There are things that I do to try to help simplify it for them, but it is ... but I’m honest with them. There are hoops to jump through.” (COC, Urban) |
| *Complex healthcare and insurance systems* | “The healthcare, health insurance system is so confusing that people don’t really, for the most part, understand whether they’re in or out of network. They don’t know what their benefits are and how they work. And a lot of times people actually have programs that are offered, like Medicare Savings programs that are offered to low income Medicare beneficiaries. And the people don’t even know that they have them and how they work to help them.” (NCI, Urban) |
| *Lack of staff to meet demand for assistance* | “I think an oncology-specific social worker is invaluable. We’re fortunate we have one, but we only have one. And I think that as hard as she works, and I mean, she works very hard, she can’t see and help every single patient. She’s just one person.” (COC, Rural) |
| *Internet and cell-phone service* | “One thing, they don’t have computer or internet. We have, I know frankly where I live, I have very poor internet service, so I don’t have the wherewithal sometimes to connect to help myself.” (COC, Rural) |
| *Insurance coverage policies* | “Now the poor people, though, the poor older people who only have traditional Medicare, that’s the gap, because they can’t ever afford to pay their deductible, and they’re only paying that 20%, they can never just do that. So, the hospital will help pay for their visits and such, but it’s not always where they’re poor enough to get 100% paid by the foundation, or from the hospital.” (NCOC[d], Rural) |
| *Limited availability of financial assistance resources* | “I would say access to resources. I feel that in an urban setting, there is a wider variety of community resources to potentially tap into.” (COC, Rural) |
| Patient-Level | |
| *Embarrassment or reluctance to discuss finances* | “I think there’s a personality difference, or there’s a life style difference. Much more an individualistic kind of philosophy..” (COC, Rural) |
| *Low health literacy* | “I do notice that our rural folks have less healthcare understanding, which is understandable especially if you just don’t have exposure. Not that they’re not teachable, but it’s just that they don’t have an understanding.” (COC, Urban) |
| *Language barriers* | “Yes, the rural community, they really struggle with language resources. A lot of times we have a bigger ethnic group coming from those areas, and there are very little like interpreter services in the smaller communities.” (COC, Urban) |

[a] – FSC=Free-standing clinic

[b] – COC=Commission on Cancer accredited

[c] – NCI=NCI Designated Facility

[d] – NCOC=Non-Commission on Cancer accredited

## Table 4.

How Care Teams Assess and Address Financial Hardship

| Theme | Representative Quote (Cancer Program Type, Rural/Urban) |
|---|---|
| **Automatic assumption that patients will have financial hardship** | "We usually just assume that they do when we talk to them, because we recognize that nobody has plans for this. What we do is just kind of tell them about the support that's available to them. We try to normalize it; that it's not uncomfortable to ask for financial assistance; that this is something that is available for everyone and that it doesn't matter." (COC[a], Urban) |
| **Multiple methods used to identify patients with financial hardship** | "For one of us financial counselors, it can be brought up many different ways. A patient can come into our offices, we can receive them from phone calls, we can get information from one of the nurses if a patient is expressing financial concern prior to an appointment, during an appointment." (Non-COC[b], Rural) |
| **Assessment through new patient consultations** | "So, any time we get a new patient and any time someone goes on treatment, we have a consultation with them, and the patient gets set up to meet with me, and then I go through and I make sure that they're set up to have a financial counselor see them...that financial counselor will do what they can in terms of the financial services if they haven't done it already." (Non-COC, Rural) |
| **Screening tools** | "...just to get a baseline and to kind of see where they are emotionally, family issues, practical issues, financial, insurance, transportation, those sorts of things and then just kind of review that with them and try to address any issues that they indicate...if a patient scores above a certain level, we rescreen them and readdress those issues with them until hopefully we get those resolved." (Non-COC, Rural) |
| **Assessing patients referred by other staff or providers** | "Now, in addition to that, if a nurse or one of the oncologists or anyone feels that a patient would benefit from meeting with me, then I'll get referred that way." (COC, Rural) |
| **Insurance status as an indicator for financial hardship** | "Well the first clue to something like that would be when we get a referral and see that the patient doesn't have any insurance, any medical insurance. Those would become a priority for us to meet with and refer and try to help them get hooked up with financial resources whether it be commercial insurance or Medicaid or whatever." (NCOC, Rural) |
| **Treatment type as an indicator for financial hardship** | "if we know the patient is gonna be prescribed an oral chemotherapy agent. The conversation for IV chemotherapy may be not until we hear back from the Precertification Department that says the patient will be financially responsible. So that conversation may take later you know over the phone." (NCOC, Rural) |
| **Alternative avenues to identify patient concerns or educate patients** | "We also, all our new patients are getting chemotherapy, are having education day, and it's an education day for them only. It's not a group education day. So, they're more freely able to speak about things in that in during the education day, we actually do...we use the stress thermometer and we do have them complete that and although that doesn't come directly to me, that goes to our social worker, so. It's kind of a group effort." (COC, Rural) |
| **Limited capacity to address needs for every patient** | "There are some that probably get slipped by. They come in with some other kind of pressing issue, and you're so busy focusing on that sometimes you forget to say, "Okay. Don't forget to find me if you have this issue, all right?" If I'm meeting somebody who's newly diagnosed...and they're upset and I'm just doing some counseling and helping them cope and get through..." (COC, Urban) |

[a] – COC=Commission on Cancer accredited

[b] – non-COC=non-Commission on Cancer accredited