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Financial hardship screening among Native American patients with cancer: a qualitative analysis

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Abstract

Background Cancer-related financial hardship is an increasingly recognized concern for patients, families, and caregivers. Many Native American (NA) patients are at increased risk for cancer-related financial hardship due to high prevalence of low income, medical comorbidity, and lack of private health insurance. However, financial hardship screening (FHS) implementation for NA patients with cancer has not been reported. The objective of this study is to explore facilitators and barriers to FHS implementation for NA patients.

Methods We conducted key informant interviews with NA patients with cancer and with clinical staff at an academic cancer center. Included patients had a confirmed diagnosis of cancer and were referred to the cancer center through the Indian Health Service, Tribal health program, or Urban Indian health program. Interviews included questions regarding current financial hardship, experiences in discussing financial hardship with the cancer care and primary care teams, and acceptability of completing a financial hardship screening tool at the cancer center. Clinical staff included physicians, advanced practice providers, and social workers. Interviews focused on confidence, comfort, and experience in discussing financial hardship with patients. Recorded interviews were transcribed and thematically analyzed using MAXQDA® software.

Results We interviewed seven patients and four clinical staff. Themes from the interviews included: 1) existing resources and support services; 2) challenges, gaps in services, and barriers to care; 3) nuances of NA cancer care; and 4) opportunities for improved care and resources. Patients identified financial challenges to receiving cancer care including transportation, lodging, food insecurity, and utility expenses. Patients were willing to complete a FHS tool, but indicated this tool should be short and not intrusive of the patient's financial information. Clinical staff described discomfort in discussing financial hardship with patients, primarily due to a lack of training and knowledge about resources to support patients. Having designated staff familiar with I/T/U systems was helpful, but perspectives differed regarding who should administer FHS.

Conclusions We identified facilitators and barriers to implementing FHS for NA patients with cancer at both the patient and clinician levels. Findings suggest clear organizational structures and processes are needed for financial hardship to be addressed effectively.

Keywords Native American, Cancer, Financial hardship

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Introduction

Cancer-related financial hardship is an increasingly recognized problem for patients, families, and caregivers [1–8]. As a relatively new field of study, financial hardship screening among patients with cancer is being studied in diverse settings with diverse instruments [9]. In a recent study, researchers looked at both medical and nonmedical financial hardship and sacrifice among patients with cancer in the general, all-races US population. Medical financial hardship included domains such as material (bankruptcy), psychological (stress related to paying bills), and behavioral (delaying care due to cost) whereas nonmedical financial sacrifice contained categories like savings depletion and changes in spending. More than 38% of study participants had to make financial sacrifices and 42% reported medical financial hardship [6]. Other studies that focused on the association between cancer and financial hardship similarly discovered financial sacrifices resulting from cancer treatment [10–13]. Such hardship has been linked to limited care, worse treatment adherence and poor health outcomes [7, 14, 15].

Financial hardship may be worse in some racial minority populations than in the general population [6, 16–18], but cancer-related financial hardship for Native American (NA) patients has rarely been reported. Many NA patients, including persons of American Indian (AI) or Alaska Native descent, may be at increased risk for cancer-related financial hardship due to highly prevalent factors, such as low income, medical comorbidity [19], and lack of private health insurance coverage. Although a few studies of NA patients with cancer included a measure of anxiety or stress due to costs of care [20, 21], financial hardship was not the focus of these studies.

Further, the systems of care utilized by many NA patients are unique, have a complex history, and often poorly understood [22]. NA patients are eligible to receive medical care coverage from an Indian Health Service (IHS) facility, a tribal health facility, or an IHS-supported urban health program, collectively abbreviated as "I/T/U" programs [23, 24]. The IHS is a federal program that operates a network of hospitals and clinics in the United States (US). Tribal Health Program hospitals and clinics are operated by individual tribes, which also receive federal (IHS) funding to care for NA patients. Urban Indian Programs are independent organizations that receive IHS funds for NA patients. Marked differences in coverage exist between I/T/U programs, which also differ from other payers. Most I/T/U programs have limited resources and are severely under-resourced for cancer care and must refer patients to outside entities [24]. Unfamiliarity with the I/T/U systems of care or payment at the outside entities can lead to confusion and delays in oncologic referrals and treatment for many NA patients.

Although studies have evaluated financial hardship among NA patients with cancer, no study of implementing a FHS tool among NA patients with cancer exists in the current literature. NA patients with cancer in one study often reported financial barriers to care [20] as well as lack of coordination between systems of care as a major barrier to care [20, 25]. Male caregivers of patients with cancer on a reservation in the American Southwest more often identified financial burden of caregiving as their leading concern than did female caregivers [26].

Potential facilitators and challenges to screening for cancer-related financial hardship for I/T/U patients have not been previously studied. Studies of cancer-related financial hardship in other populations may not reflect those faced by patients who depend on I/T/U systems of care for coverage.

The I/T/U system in Oklahoma includes approximately 50 federally operated health centers or hospitals, tribally operated health centers or hospitals, and urban outpatient facilities. Oklahoma has the largest tribal land area in the US. At the time of the study, more than 14% of citizens (~ 483,000) identified as NA either alone or in combination with another race, the highest proportion in the US [27]. Incidence and mortality rates from high-priority cancers are especially alarming for the state's NA population, with 1.4 and 1.8 times higher mortality for lung and colorectal cancer, respectively, compared with the non-Hispanic White state population [28].

To design and implement a pilot FHS program for NA patients referred to a cancer center in Oklahoma, we obtained stakeholder views on facilitators and challenges to FHS. This manuscript includes findings from the first objective of a three-part study. Findings from subsequent parts of the study, including pilot FHS implementation and evaluation, will be presented elsewhere. We hypothesized that themes specific to NA patients referred by I/T/U facilities would emerge that inform the design and implementation of FHS for these patients. We also hypothesized that designated referral coordinators, or navigators, for I/T/U patients at the cancer center would be considered as helpful initiators for FHS. This study reports findings from patient, clinical provider, and clinical staff key informant interviews that identify several facilitators and challenges to consider when designing FHS. The results support FHS that considers facilitators and challenges related to I/T/U systems of care, as well as the role of designated staff familiar with these systems.

Methods

This descriptive case study research design uses qualitative methodology and a stakeholder-engaged approach [29–31] with semi-structured interviews to gather diverse perspectives related to FHS implementation for NA patients. This approach helps identify specific contextual facilitators and barriers to implementation that may not have been identified in other healthcare settings.

The setting for the study is the Stephenson Cancer Center (SCC), affiliated with the University of Oklahoma Health Sciences, opened in 2011. In recognition of the need for expertise in I/T/U health systems SCC created the American Indian Navigation Program (AINP). Of 20,540 patients at SCC in 2019, NA patients accounted for 6.4%, with more than half referred from I/T/U facilities across the state. From 2017–2019, 1,222 new I/T/U patients from multiple federally recognized tribal nations received AINP services. The American Indian Navigators (AINs) see any patient referred from an I/T/U facility, regardless of the type of cancer diagnosis.

The interview guides were developed for this study. In February 2021, the research team met with a 10-person stakeholder advisory board consisting of I/T/U and SCC clinicians, staff, and a NA patient for feedback regarding a semi-structured, open-ended instrument to guide patient (Patient Interview Guide) and provider (Provider Interview Guide) interviews. The Consolidated Framework for Implementation Research (CFIR) [32] served as the conceptual model for the guide to ensure consideration of factors that may influence financial hardship screening for NA patients with cancer [33]. The CFIR includes five domains (intervention characteristics, outer setting, inner setting, characteristics of individuals, and process) that may affect the implementation of a new screening process.

Key informants for semi-structured interviews included NA patients as well as clinic providers and staff at SCC. We used purposive sampling to recruit within the identified clinics as both patients and providers. Signed informed consent was obtained for all participants.

Eligibility for patients to participate as key informants included being NA, referred from an I/T/U system, ages 18 years or older, diagnosed with cancer, and currently receiving cancer care at the SCC. Project staff reviewed patient lists of potentially eligible patients and advised on which patients to recruit for this project based on general health status and reason for the visit (e.g., standard follow-up or chemotherapy visit). Patient participants completed a brief questionnaire immediately following the interview to collect demographic and clinical information, including cancer diagnosis and date of diagnosis as well as gender, race, ethnicity, age at diagnosis, highest level of education, and household income.

Eligibility for SCC personnel included being a provider (physician, physician's associate, nurse practitioner) or clinical or support staff (clinic or nurse manager, case manager, social worker) at an SCC clinic. Providers were recruited through all-staff emails sent to SCC staff. SCC providers and staff completed a brief questionnaire to include demographics (gender, race, ethnicity, and age), years in practice, and their roles at SCC.

All patient and provider/staff participants were individually interviewed either in-person or by teleconference (Zoom) in sessions lasting less than one hour. Interviews were digitally audio-recorded and transcribed. Transcribed interviews were checked for accuracy and uploaded into MAXQDA for analysis [34]. Two research team members reviewed the transcripts, developed the codebooks, and coded interviews together to ensure cultural nuances were captured. Independent codebooks for provider and patient interviews were developed and revised. To enhance rigor and reproducibility, codes were developed and revised through an iterative process. Integrated approaches of inductive and deductive analysis have been shown to provide a more comprehensive perspective of the phenomenon of interest [35]. Codes were first developed using the key informant interview guides and subsequently revised as relevant patterns emerged. Through routine discussion, agreement of coding structure and definitions was achieved. Codes were reviewed and patterns were identified in each data set, presented below as themes. Findings from the analysis were shared with the research team and Stakeholder Advisory Board.

Results

As noted, eight patients consented to the interview, and seven (four female, three male) patients completed the interview. Three patients were aged 35–54 years and four were 65 years and older. Four participants had lung cancer, and the three others had different cancers. Four were currently in treatment for their cancer, with two determining the treatment plan and one obtaining follow-up care from initial surgery. Provider and staff participants varied in position and included two Physician Assistants, one Social Worker, and one Surgical Oncologist. Years of practice ranged from four to 16 years.

Themes identified for both providers/staff (herein simplified to "providers") and patients included: 1) existing resources and support services; 2) challenges, gaps in services, and barriers to care; 3) nuances of American Indian cancer care; and 4) opportunities for improved care and resources.

Existing resources and support services

Provider

Providers reported complexities in coordinating care for the NA patients. Interfacing with I/T/U health systems was identified as a challenge, particularly the inability to electronically prescribe medications, requirement to have certain orders completed at the referring facility (e.g., CT scans completed at the I/T/U facility instead of the cancer center) and obtaining pre-authorization for certain procedures to be completed at the cancer center. Providers perceived that the pre-authorization process delays care in some cases. While requiring patients to have orders completed by their referring I/T/U is also perceived as a barrier to some providers, others reported that this requirement benefited some patients by not having to make multiple trips to the cancer center. To reduce patient travel, some providers reported strategically scheduling multiple appointments on the same day.

Patient

Patients reported that their respective I/T/U provided support in a variety of capacities, including direct financial support with the amount and availability of support varying by site. Other types of support provided to participants by I/T/Us included gift cards to purchase gasoline for their vehicle, housing and utility assistance, and food assistance. In addition to financial support, some participants reported that their I/T/U provided support with their cancer care coordination by navigating the referral process, explaining the treatment plan, and prioritizing patients with cancer so that services and referrals can be completed in a timely manner. Other participants had to rely on alternative, pre-existing sources of funding and insurance to support themselves during treatment, such as Veterans Affairs, Medicare, Medicaid, or Social Security to make ends meet. Other sources of financial support reported by participants included personal savings accounts, unemployment, and tribal resources.

Patients identified resources to aid in the care coordination process, including navigation assistance at the cancer center, the I/T/U facility, and family support. Some patients relied solely on cancer center navigation services, whereas others received additional care coordination services at their referring I/T/U. One patient had received a medical bill from the cancer center but after sending to their I/T/U representative, the bill was paid in full, and the patient's burden was alleviated. Regarding family support, most patients reported having a strong support system, relying on spouses, children, grandchildren, and parents to alleviate burdens related to their cancer care. Family support included providing transportation to cancer treatment, advocating for patient needs, coordinating cancer care, and identifying financial resources. Some patients described their family support systems more broadly, whereas others identified specific instances where family had assisted. One patient recounted the support their spouse provided, indicating that their life was saved as a result of them encouraging the patient to schedule an initial appointment. Participants also reported that their families provided financial support, assisting in several capacities ranging from bills to their children's school uniforms.

Challenges, gaps in services, and barriers to care

Provider

All providers reported familiarity with the cancer center's AINP and described the AINs as helpful for both providers and patients and critical mediators between I/T/Us and the cancer center. Although providers perceived the AINs to be communicative, some expressed a desire to have them become more accessible and embedded into their clinic. Providers felt that the limited number of AINs was a potential barrier to expanding navigation services, including financial hardship screening. Several barriers to treating NA patients were reported by providers. Staffing limitations have resulted in the inability to implement screening tools, embed necessary staff within the clinic, or adequately address financial challenges faced by patients. Providers noted the need for better clinical integration of social workers and financial navigators and suggested that having a point of contact within social work would promote care coordination and relationship building between patients and clinical staff. Challenges related to tribal health referrals were also identified as a barrier to care. Providers described challenges in discussing financial hardship with patients. Given the variety of roles among providers, the degree of comfort in discussing financial hardship varied. Providers who routinely refer patients to resources considered financial-related conversations to be part of their job responsibility, whereas those directly involved in medical care experienced discomfort in having these conversations (Table 1).

Providers reported that some NA patients experienced reduced quality of care, compared to other patients, due to the unique health system features as previously described (inability to electronically prescribe certain medications, requirement of imaging and/or lab tests to be completed at the I/T/U facility), and the mandatory pre-authorization process. A major challenge reported by multiple providers was transportation, with resources including transportation services for low-income participants through Medicaid, gas reimbursement using small emergency funds, or charitable donations. Other patient challenges included maintaining employment and few resources for childcare.

Table 1 Challenges, gaps in services, and barriers to care

Provider Quotes	Patient Quotes
• "I feel comfortable having many difficult discussions about death and dying and depression but finances, I probably feel less comfortable with just because it's not something we're taught, and I don't want to make the patient feel uncomfortable, even though it's probably something they need to talk about. And because I don't know what to do for them sometimes, I mean besides sending them to someone else or the social worker. I don't always feel like I know how to improve that situation, so it's a hard conversation to have." CI4	• "Cause that was one of the main things that really was on my mind almost every day. Is, I can go without a car. I can, you know, I have family I that I can stay with if it ever came to not being able to pay rent…but, you know, something to eat is something else" PT6
• "I had a patient who…needed surgery and we had it scheduled, and the tribe actually wanted to get him on Medicare expansion…to cover it…We sort of got that message late and then it delayed the surgery once and then…we didn't get told that that change had happened, and so it delayed the surgery a second time. And I just felt really horrible for the poor guy." CI5	• "Well, we are on uh social security. And so, we only get so much a month and to come down here to Oklahoma City, it costs us anywhere from $150 to $200 dollars if we spend the night. For gas, motel, and eats. And we don't eat much, you know, we just eat out cheaply." PT8

Patient

Patients identified multiple financial challenges to their cancer treatment, primarily related to logistics, such as transportation, lodging, and food during travel to the cancer center. The AIN team and I/T/Us could provide resources for some patients, including gas cards, hotel vouchers, and support for housing, utilities, and children. However, the I/T/Us primarily provided these resources, which were nevertheless limited, with some participants noting that there were no funds available when they inquired about them. Participants frequently relied on a family member for transportation to the cancer center, adding stress for the participants in arranging consistent transportation. While some transportation options are available through Medicaid, some patients lived outside of the radius for this transportation service.

Multiple patients reported unanticipated challenges during their cancer journey and concerns related to the financial impacts on their families. These included not knowing what to expect of cancer treatment after a recent diagnosis, transportation, and coping with changes to physical appearance after cancer-related surgery. The COVID-19 pandemic was also noted by multiple participants as affecting their ability to attend appointments and being generally disruptive.

Multiple patients reported psychosocial stress, including transportation concerns, stresses in their work environment, food insecurity, having enough funds to care for family and required medical treatment. Resources that patients described included Family Medical Leave Act, family support, and tribal resources (though these were limited). Patients reported that they relied on their faith and their family for support during stressful situations, like cancer diagnosis and treatment. Some patients reported stress associated with a cancer diagnosis, side effects of their cancer treatment, and challenges with pre-existing health conditions. Participants also identified challenges related to the management of taking new and numerous medications, pre-existing mobility, and vision impairments, and maintaining the right state of mind at work.

Nuances of Native American cancer care

Provider

Providers reported several nuances in treating and providing services to their NA patients. The logistics in care coordination between I/T/U systems and SCC were described as a challenge by some providers. Other challenges acknowledged by providers included lack of accommodations and travel support for long distances required for patients to travel for cancer care. Some providers had misconceptions of resources available to NA patients, with some believing that NA patients have more resources, whereas others believed they have fewer resources. One participant reported that although some NA patients may have access to unique resources for healthcare support, they face unique system-related challenges, including a complex referral and authorization process, as described further below (Table 2).

Patient

One patient noted cultural nuances and perspectives of cancer care. This participant emphasized the importance of returning to traditional ways and communal benefit when completing the interview by stating, "You don't look out for one. You got to look out as a whole." The value of family and community involvement and support was also described as an important component of care, stating their spouse answered healthcare providers' questions because they are "just really Indian." Other patients did not note specific nuances they attributed to NA differences in health care systems.

Table 2 Existing support and nuances of Native American cancer care quotes

Provider Quotes	Patient Quotes
Existing Resources • "So, our Indian Health navigation team is a really small team…I know they stay very, very busy…They're trying to coordinate a lot of different things for our patients…my experience with them is they have been very helpful. Usually when I'm in touch with them-it's, I have, like a specific question about, you know, 'This patient lives in McAlester and is needing help to get transportation. Do you know what tribe they belong to? Do you know if that tribe helps with transportation assistance?'…and generally speaking, they have been very helpful." CI1	Existing Resources • "Yeah, my tribe is, they help but they only help, you know, about every three, six months, you know." PT 6 • "During that transition, I did receive a bill from OU, but all I had to do was…I emailed a copy of it to my Indian representative there at [referring tribal nation] …and she said she'd take care of it, and…she got it properly filled out through the referral…[referring tribal nation] has taken care of all of my treatment cost and everything." PT7
Cultural Nuances • "For us, at least on my provider side, it's interfacing with the Indian health system is where things get complicated. Some of the medications have to go to the Indian health pharmacy. Those can't be prescribed electronically. I have to do a printed prescription and I either fax them or give them to the patient, which gets a little more complicated than if I just put a prescription normally through the computer. Especially with like ordering CT scans to follow up on their cancer. The Indian health system usually wants those scans done there because that's a service that they provide. But a lot of times, their scanners aren't as good as the ones that we have here, so then we fight with them to try to get their scans done here. And that's a lot of back-and-forth for both the patient trying to integrate those two systems of what will Indian health pay for and what do I have to pay for." CI3	Cultural Nuances • "And I speak on that behalf and not just because of myself but…for all other patients that come through there…you don't look out for one. You got to look out as a whole…You got to expand your visions. And not just for yourself." PT3

Opportunities for improved care and resources

Provider

Providers described several opportunities for improvement to better address the needs of NA patients. While some providers were less familiar with current financial hardship screening protocols, most participants indicated that screening strategies needed to be enhanced and better integrated into clinical workflow. Providers noted that financial hardship extends beyond the inability to pay medical bills; therefore, screening should also include food insecurity, transportation barriers, and challenges in filling prescriptions. Some participants expressed a desire to be more knowledgeable about anticipated financial hardships and resources for patients, in addition to having increased access to social workers.

Discomfort in discussing financial hardship was reported to be a result of the limited knowledge of resources and lack of adequate training in having financial-related conversations. Providers were not consistent in addressing FHS with all patients but would discuss if the patient asked a question. Providers reported that AINs and social workers were better equipped to aid patients with financial concerns. However, most providers expressed interest in training related to financial hardship screening, including skills for administering screening tools, resources available for patients, and awareness of patient needs (Table 3).

Providers had differing perspectives of patients' comfort in discussing financial hardship, although some providers recognized that each patient is unique in their willingness to discuss their finances. According to some providers, some patients are upfront about their financial needs whereas others are willing to discuss challenges only if inquired. Providers suggested standardizing the FHS process so that patients are screened as a result of protocol, rather than after a patient expresses a concern. Providers recommended FHS that is thorough and specific yet brief enough for patients to complete routine paperwork. Opinions about who should conduct FHS varied among providers. Clinicians stated they rely on other staff (like social work or navigators) to address financial issues, unless the financial issue is obvious (e.g., missed appointments). Providers reported that, ideally, FHS would occur with the patient's primary care provider, but many patients do not receive consistent primary care.

Participants stated that incorporating FHS into the standard EMR workflow, including automatic referrals and routine screening, would allow FHS to fit well within the current distress/social work referral process. FHS should be done routinely (e.g., every 6 months). Providers consistently stated that the first appointment with the SCC team for a newly diagnosed cancer was not the ideal time to address financial hardship due to the overwhelming nature of a cancer diagnosis. Ideally, AINs, social work, and nurse/financial navigators would be more accessible to address financial concerns as they arise.

Table 3 Opportunities for improved care and resources

Provider Quotes	Patient Quotes
• "It's important to, to be screening all patients. Maybe come up with like uh a normal interval at which you would screen, maybe once every six months while they're in active treatment…I think it's important to normalize those kinds of screens…like, 'this is something we ask of all of our patients because we know it's something that a lot of our patients deal with.' I think something that's nice about a written screen is usually you can make those pretty short and sweet, so it's just kind of a normal part of paperwork you fill out when you go to the doctor. It can feel a little bit more private…if you're able to just fill out a couple questions and turn in a piece of paper to your doctor. That's a little easier than someone asking you, 'Have you had trouble filling your prescriptions this month?'" • "I think maybe now our nurse navigator does a little bit more screening of new patients coming in. I don't think that necessarily picks up on patients having a change in their finances as they go through this process because they might be stable when they start, but as all these bills come in, I think their situation changes and we don't probably reassess that." CI4	• "I mean the initial checking on someone's financial status while they're going through the treatments, surgeries, or just regular checkup appointments is definitely something that can be helpful. I'd kind of gotten myself sorted out mostly before now and like I said, thankfully I had family to lean on, but there are some people that don't and that is definitely something that I would, I would, you know, 100 percent support." PT7 • "Moderator: What points of your cancer journey would you prefer to talk about your financial challenges? Patient: I would say in the middle. Because you just don't know what, you know, your appointments are going to be. You don't know um how long your appointments are going to be…Maybe after you get a better idea of how many and the extensiveness of your treatment." PT9

Patient

Patients reported differing perspectives of financial hardship discussions and screening. While some patients indicated that someone on their healthcare team should be aware of financial challenges patients experience, others stated that inquiring about financial situations could feel like prying if resources were not available to address challenges. Among those who were comfortable with screening, some patients stated no preference of length as long as questions were not repetitive, whereas others preferred a shorter length – one page, 8–20 questions, or 1–15 questions. There were also differing preferences on when and how frequently the screening tool should be implemented. Some patients indicated that the screening tool should be completed at the initial diagnosis so that financial challenges are identified early in the process, whereas others reported that screening should occur after a treatment plan has been established due to the unexpected nature of many emerging financial challenges. Patients reported differing preferences on how the screening was completed, with some preferring in-person at their appointment and others over the phone. Generally, participants reported few financial related topics to avoid in screening for financial hardship, however discussions related to savings, credit standing, and long-term financial situation should be avoided. Some patients also identified a specific member of their healthcare team who they would feel most comfortable having financial related conversations with, including their provider or AIN. Some patients reported that resources are challenging to identify at times and having their healthcare team screen for anticipated challenges would reduce financial distress.

Most patients reported that their healthcare team had not discussed financial related challenges in the past, although resources such as transportation assistance and lodging had been offered. Some patients reported that they had not discussed financial hardship related to their cancer care with their I/T/U or referring provider, however some were informed that their treatment would be paid for by their referring I/T/U or that an AIN at the cancer center would assist with financial challenges that may arise. Patients were inconsistent in their perceptions of their healthcare team serving as a resource. Some patients reported that their healthcare team could provide financial resources, including gift cards, whereas others indicated that financial support services were not available for patients. All patients reported either working with an AIN or being willing to work with one to aid in care coordination processes. Additionally, the interactions with AINs ranged from having no recollection of working with them to routine interactions. Some patients indicated that having an AIN was a helpful resource, citing their role in securing lodging and transportation assistance during their cancer treatment. However, others were unaware of AIN services or confused about their role. Some unfamiliarity with AINs was attributed to family members serving as a liaison between the providers and the patient. Patients who were unaware of AIN services often reported that they would like to be connected.

Limitations included a small sample size due to recruitment challenges which may limit generalizability to larger populations. Another limitation were clinical workflow constraints which may have resulted in inhibited responses. In addition, as the study was conducted at a single cancer center, its findings may not be generalizable to all healthcare settings serving Native American patients.

Discussion

Using a stakeholder approach for perspectives on implementing FHS for NA patients with cancer at an academic cancer center has revealed challenges and opportunities for both the cancer center and I/T/U systems. FHS was considered by both patients and providers as potentially beneficial to patients, as NA cancer care-related issues generally revolve around the different systems of care between I/T/U and non-I/T/U facilities. Having a designated team of navigators with expertise in the unique requirements of I/T/U patients was considered beneficial to both patients and providers. The need for more AINs was identified, especially if adding FHS to their roles. Structural systems to integrate FHS with both cancer center and I/T/U resources to address potential needs were viewed as potentially improving care by reducing delays in care or access to treatments. By integrating the CFIR framework within the interview guides, we ensured that each domain of CFIR was addressed, which will support development of future intervention strategies that account for each domain and provide the best opportunity for success. We included questions about future implementation of a financial hardship screening tool to assess comfortability and potential acceptability of questions related to financial hardship. By talking with both patients and providers, we were able to assess the outer setting (features of the external environment) and inner setting (organizational factors that may influence the intervention). We evaluated the characteristics of individuals by asking about their knowledge of financial hardship resources and financial needs during cancer treatment. By including questions of both patients and providers about what factors or strategies may influence implementation, we evaluated the process domain.

The reliance upon family was prominent and has emerged in other studies of NA patients with cancer, reporting that many NA families provide more than just emotional support [25]. While HIPAA presents challenges in the engagement of family, opportunities to expand involvement more systematically when requested by the patient exist.

While generally favorable to FHS, patients and providers differed in opinions regarding implementation. Training providers to undertake FHS and discuss financial concerns would be an opportunity to improve financial communication with patients. Adding FHS to the experience of receiving cancer care, however, may add to an often-overwhelming process. A study of NA patients found that excessive "paperwork" was a frequently noted barrier to cancer care [36]. The ideal implementation for asking and addressing financial barriers to care is currently being studied across the nation in diverse settings.

Conclusions

This study made identified several factors to consider when implementing FHS for NA patients referred to a cancer center. It employed a stakeholder approach to gather perspectives from both Native American cancer patients and cancer center providers on implementing FHS which allowed identification of facilitators and barriers to FHS implementation at both patient and provider levels. As hypothesized, specific I/T/U-related themes emerged, including both facilitators and challenges regarding coordination and coverage for care as well as varying degrees of cancer center and I/T/U support for indirect costs of care, such as transportation and lodging. Also as hypothesized, having AINs familiar with I/T/U systems of care were overall viewed by both patients and providers as useful in facilitating access to cancer work up and treatment, but additional staffing was identified as needed for implementation of FHS. Importantly, the study gathered culture-specific perspectives on the acceptability of FHS for Native American patients, addressing a gap in the literature. The application of the CFIR ensured a comprehensive assessment of factors influencing potential FHS implementation, providing a structured approach understanding the complex issues involved.

Theoretically, this research highlights the importance of considering cultural nuances and unique health system features when implementing FHS for Native American patients, emphasizing the need for culturally tailored approaches in healthcare interventions. The research demonstrated the utility of using implementation science frameworks like CFIR to guide assessment of FHS implementation factors, showcasing how such frameworks can be applied in real-world healthcare settings. Additionally, the study identified the need to balance FHS with existing screening burdens on cancer patients, pointing to the importance of considering the overall patient experience in healthcare interventions.

From a practical standpoint, the study offers several important insights. It suggests that clear organizational structures and processes are needed for financial hardship to be addressed effectively in healthcare settings. The findings indicate a need for provider training on conducting FHS and discussing financial concerns with patients, highlighting an area for potential improvement in patient care. The study also points to opportunities to better integrate American Indian Navigators and social workers into clinical workflows to address financial hardship. From a patient's view, it highlights the need to understand the impact that family playsin FHS. Most importantly, this study suggests that FHS should be brief, routine, and integrated into existing clinical processes to be most effective and feasible.

A systematic review estimated that nearly half of individuals with cancer experience financial hardship [19]. It is associated with delays in cancer care and poor clinical outcomes [37–39]. The reasons for these adverse effects may reflect the multidimensional nature of financial hardship that encompasses: 1) direct consequences of treatment (e.g., out-of-pocket expenses, debt, and decreased income); 2) psychological distress because of costs; and 3) deleterious coping mechanisms (e.g., delaying or skipping medications or care) [40]. Because our study begins to address the important question of what financial hardship means for NA patients with cancer and their clinicians, our findings provide insights preparatory to future research to explore the underlying elements of financial hardship in relation to adverse health outcomes in NA patients.

In particular, our findings suggest that research on financial hardship among NA patients with cancer should examine the extent to which tribes and the I/T/U system can help address financial concerns, as the availability of tribal or I/T/U resources appears to be inconsistent. NA patients also emphasized the centrality of family and community in addressing financial issues, indicating that research examining the role of families in addressing financial hardship concerns is warranted.

A growing body of research suggests that implementation of navigation services for patients with cancer may help address financial hardship [41–43]. While some studies have examined NA-specific navigation programs [20, 43–47], these studies have not focused on navigation that includes systematic financial hardship screening. Thus far, NA navigation programs have concentrated primarily on helping NA patients coordinate cancer care between oncology clinics and the I/T/U system. Successful NA navigation programs [20, 43–47] are community-based and focus on patient needs, including barriers to accessing cancer care, cultural concerns, and education about cancer and treatment options [48]. Two studies have evaluated stress and anxiety due to the cost of cancer care among NA patients [20, 21], but none included systematic financial hardship screening. Thus, research is needed to further investigate the potential impact and sustainability of navigated FHS interventions to help address financial concerns and enhance the care experience of NA patients with cancer. In particular, our findings suggest that research examining the implementation of systematic financial hardship screening should explore the questions of who should administer screening (e.g., navigators versus clinicians), how detailed the screening should be, and how frequently it should occur. Our findings also suggest that staffing limitations impede the ability to conduct financial hardship screening. Because the Centers for Medicare and Medicaid Services now provides coverage for cancer navigation services for persons with Medicare coverage [49], research could be conducted to determine whether this new CMS benefit can meaningfully support navigation services addressing financial hardship for NA patients with cancer.

This study had several limitations. Patient recruitment strategies interrupting clinical workflow and time restraints resulted in a small sample size for this study. We also experienced challenges in recruiting clinicians, likely due to clinical time restraints and unfamiliarity with FHS practices. While a broad range of NA perspectives were captured, tribal and cultural variance could be broadened in future studies. Conducting interviews with patients in a clinical environment may have inhibited their ability to adequately reflect and respond to the question guide. Similarly, provider interviews occurring outside of clinical hours may have allowed for enhanced responses. Future studies should examine culture-specific perspectives on the acceptability of FHS.

In conclusion, our study identified both facilitators and barriers to implementing FHS at a single cancer center among NA patients. Future studies should seek to understand the role of FHS in the context of the myriad of screenings cancer patients receive during treatment, in addition to the timing and frequency in which FHS should occur.

Abbreviations

NA	Native American
FHS	Financial Hardship Screening
I/T/U	Indian Health Service (IHS) facility, a tribal health facility, or an IHS-supported urban health program
SCC	Stephenson Cancer Center
AINP	American Indian Navigation Program
AINs	American Indian Navigators
CFIR	Consolidated Framework for Implementation Research
US	United States

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Authors' contributions

ASAB analyzed and interpreted the data and drafted the initial manuscript. AEJ analyzed and interpreted the data and drafted the initial manuscript. MPD provided guidance on interpretation of data and contributed to writing the manuscript. SDM provided guidance on interpretation of data and contributed to writing the manuscript. MAK contributed to data collection. KLH contributed to data collection and provided guidance on interpretation of the data. MBB contributed to data collection and provided guidance on interpretation of the data. SD contributed to data collection and provided guidance on interpretation of the data. SKB contributed to writing the manuscript. DAR provided guidance on interpretation of data and contributed to writing the manuscript

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Availability of data and materials
Data are not available to be shared due to confidentiality issues.

Declarations

Ethics approval and consent to participate
The study was approved by the Oklahoma Area Indian Health Service Institutional Review Board (Protocol Number P-21–01-OK) and the University of Oklahoma Health Sciences Institutional Review Board (Protocol Number 12659). All participants completed written or electronically signed informed consent.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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