Provider Communication: The Key to Care Coordination Between Tribal Primary Care and Community Oncology Providers

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PURPOSE: To explore tribal primary care providers' and community oncology providers' experiences of caring for individuals with cancer to inform intervention development and improve cancer care coordination in this high-need population.

PARTICIPANTS & SETTING: 33 tribal primary care providers and 22 nontribal, community-based oncology providers.

METHODOLOGIC APPROACH: A qualitative, descriptive design was used, and 55 semistructured individual interviews were completed. Data were analyzed using conventional inductive content analysis to identify major themes.

FINDINGS: Effective care coordination for individuals with cancer was characterized by timely communication. Providers in both settings identified unhindered communication between providers as a key element of care coordination. Identification of points of contact in each setting enhanced information exchange. As patient needs related to cancer care intensified, care coordination increased in complexity.

IMPLICATIONS FOR NURSING: Evaluating strategies to enhance communication between tribal primary care providers and community oncology providers is an important next step in enhancing the coordination of care for tribal individuals with cancer.

KEYWORDS care coordination; communication; primary care; tribal health care; providers
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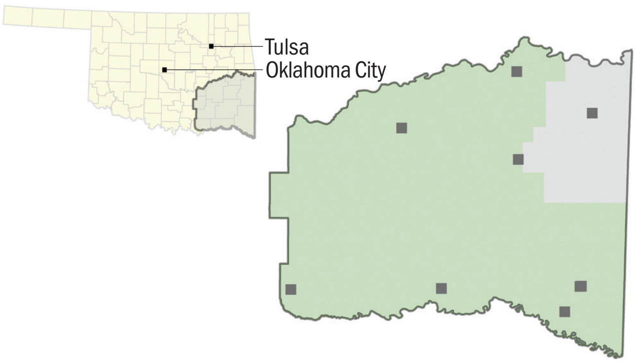
Cancer is the second most common cause of death in the United States and Oklahoma (Centers for Disease Control and Prevention, 2021; Heron, 2021). In 2019, about 13% of Oklahoma's population was American Indian/Alaskan Native (AI/AN) race alone or in combination with one or more other races (U.S. Census Bureau, 2019). The patterns of cancer occurrence among AI/AN populations are distinctive because of their unique history, culture, geographic location, and access to health care (Cobb et al., 2008; Koh, 2009; Levine et al., 2014). Among the major risk factors for cancer, commercial tobacco use and alcohol misuse, lower physical activity levels, and high levels of obesity have been observed at greater rates in AI/AN populations (Cobb et al., 2008; Fine et al., 2004; Kagawa-Singer et al., 2010). Cancer outcomes are influenced by access to care (Yabroff et al., 2020). Reduced screening among AI/AN populations has also been attributed to the lack of AI/AN healthcare providers, culturally relevant education, and ancillary support services (Daley et al., 2012). AI/AN cultural and spiritual beliefs have been shown to influence perceptions of screening, specifically related to privacy and fear (Filippi et al., 2013). In some cases, AI/AN individuals believe that talking and thinking about cancer may result in its manifestation (Watson-Johnson et al., 2011).

Racial disparities in cancer exist (Chu et al., 2007; Li et al., 2003; Siegel et al., 2013). AI/AN populations often bear higher rates of cancer incidence and mortality; this disparity varies by geographic region and cancer site (Becker et al., 2008; Bliss et al., 2008; Espey et al., 2005; Henderson et al., 2008; Jim et al., 2008; Lemrow et al., 2008; Perdue et al., 2008; Reichman et al., 2008; Sugarman et al., 1994; Swan

& Edwards, 2003; White et al., 2014; Wiggins et al., 2008a, 2008b; Wilson et al., 2008; Wingo et al., 2008). From 2013 to 2017, more than 109,500 Oklahomans were diagnosed with cancer; 10,359 of those diagnosed with cancer were reported as AI/AN (about 10% of all cancers) (Oklahoma State Department of Health, 2020). The AI/AN population in Oklahoma also had a significantly higher age-adjusted cancer incidence rate than did the White population (642.6 per 100,000 versus 473.5 per 100,000, respectively) (Oklahoma State Department of Health, 2020). In the Choctaw Nation service area, 815 cases (540.3 per 100,000) of the 5,749 (454.4 per 100,000) cancers diagnosed from 2013 to 2017 were in AI/AN individuals (Oklahoma State Department of Health, 2020). In addition, about 23% and 46% of the AI/AN population were diagnosed at a distant stage for colorectal cancers and lung cancers, respectively, compared with about 20% and 41% of the White population (Oklahoma State Department of Health, 2020).

Many studies have reviewed segregation issues, historical trauma, racism, institutional racism, intergenerational poverty, and the lack of access to care among AI/AN populations (Graham & Gracia, 2012; Jack & Griffith, 2013; Kagawa-Singer et al., 2010). Such complexities are amplified by the highly rural nature of the 10.5 counties in southeastern Oklahoma comprising the Choctaw Nation tribal jurisdictional service area (TJSA) (U.S. Department of Agriculture, 2020) (see Figure 1). Although the Choctaw Nation TJSA faces socioeconomic challenges, the Choctaw Nation Health Services Authority (CNHSA) thrives in research, health, and cancer control operations (U.S. Census Bureau, n.d.).

FIGURE 1. Choctaw Nation Tribal Jurisdictional Service Area With Rural-Urban Continuum Code Designations and Primary Care Clinic Sites



Note. Dark gray boxes represent Choctaw Nation Health Services Authority clinics. Green shading represents rural areas, and light gray shading represents urban areas.
Note. Image courtesy of Janis Campbell. Used with permission.

Coordination of Care Complexities

Primary healthcare in AI/AN populations is provided by the Indian Health Service (IHS) or other tribally operated programs (Kunitz, 1996). Self-governance tribes, including the Choctaw Nation, are allocated annual federal funding to operate and control all health programs, services, functions, and activities (Warne, 2011). The independent nature of self-governance operations results in great variation of tribal capacity, type and quality of services offered, and individual tribal need. CNHSA is the first federally recognized tribe in the United States to independently purchase and build a hospital, and it provides quality care to AI/AN individuals through eight primary care (PC) facilities (Choctaw Nation, n.d.-b).

All enrolled AI/AN citizens are eligible to receive health services from CNHSA. Only Choctaw Nation citizens who reside within the TJSA for 180 days prior to an appointment are eligible for specialty services (Choctaw Nation, n.d.-a). Most oncology services are not available through CNHSA and require a referral through Choctaw Referred Care. Patients seeking specialty care must have exhausted all other payment and insurance resources before using referred care (Choctaw Nation, n.d.-a). Choctaw Referred Care screens patients for Medicaid eligibility when they receive a referral.

Research pertaining to the tribal cancer care coordination process is limited. A study by Guadagnolo et al. (2011) found that the integration of patient navigation in American Indian cancer treatment resulted in an increase in clinical trial enrollment and reduction of treatment interruptions. An analysis of various navigation programs for individuals with cancer found that, despite an overlap in the role of patient navigators, cultural and community contexts influenced how the navigation needs of a given community were met (Braun et al., 2012). Given the unique cultural context and lack of previous cancer care coordination research within CNHSA, this study provides an important contribution to the literature.

Coordination of care involves a multistep process, requiring additional time and referrals for specialty care. When cancer screening is initiated for a CNHSA patient, via routine screening guidelines or otherwise, it is determined whether the screening procedure is accessible through CNHSA. If the procedure is offered through CNHSA and the patient's respective

PC clinic, the screening is completed without a referral. If the screening is not accessible through CNHSA but the patient does meet eligibility requirements for Choctaw Referred Care, a referral is completed for screening to take place at an oncology facility outside of the CNHSA network. Any patient who does not meet Choctaw Referred Care eligibility requirements does not qualify for external cancer screening or treatment. If the patient received screening through CNHSA, their eligibility for Choctaw Referred Care is not determined until after the initial screening suggests a cancer diagnosis.

Should the patient be deemed eligible, an oncology consultation visit is initiated by Choctaw Referred Care to confirm cancer diagnosis. The diagnosis and proposed treatment plan are then sent to the PC provider (PCP) and/or Choctaw Referred Care, depending on the oncology practice, and to the patient. The Choctaw Referred Care committee reviews the treatment plan and provides approval in 90-day increments of care. The oncology appointment is then scheduled; on completion of the appointment, progress notes from the visit are sent to the PCP and/or Choctaw Referred Care.

One striking feature of care provided through IHS and tribal clinics is that any laboratory tests, imaging, or other orders required by oncology that are available through CNHSA must be completed within the CNHSA system rather than by the oncology practice. This added complexity requires additional referrals to be reviewed and approved by Choctaw Referred Care, patient transportation between facilities, and seamless information transfer between Choctaw Referred Care and the oncology facility throughout the trajectory of cancer care.

The Care Coordination Model provided the conceptual framework for the present study (Center for Accelerating Care Transformation, 2011). With the goal of providing patients with high-quality referrals and transitions between PCPs and specialists, the model highlights four key elements: accountability, patient support, relationships and agreements, and connectivity. Accountability addresses who is organizing the care and referrals for given patients. Patient support refers to the supports in place to address any questions about the referral process, scheduling assistance, and problem solving of any logistical issues. Relationships and agreements focuses on interprovider relationships; it is important that there is a clear understanding of provider preferences, the information needed by both parties, plans for tests that may need to be done, and expectations for reports. Connectivity addresses the exchange of information between providers (Center for Accelerating Care Transformation, 2011).

Previous research has explored the relationship between oncology providers and nontribal PCPs to identify factors influencing the process of caring for individuals with cancer along the cancer trajectory. The communication process was identified as a key factor in promoting shared care and coordination of care for patients from diagnosis through treatment and survivorship (Blaauwbroek et al., 2007; Chubak et al., 2012; Hall et al., 2011; Mitchell et al., 2012; Shen et al., 2015; Sussman & Baldwin, 2010). Studies examining the processes of care, including the coordination of care between rural tribal healthcare systems and oncology practices, are missing from the literature.

Given the abovementioned challenges in cancer care coordination, Choctaw Nation community members expressed an interest in partnering with the Stephenson Cancer Center at the University of Oklahoma Health Sciences Center in Oklahoma City to identify challenges and opportunities for improvement from the clinical perspective. This community-initiated study had three aims: (a) to identify the perceptions, knowledge, and practices regarding care coordination of adult cancer survivors receiving care through CNHSA in a sample of PCPs and oncology providers; (b) to identify challenges and facilitators of transitions from PC to oncology care and back to PC in current clinical practice; and (c) to describe key aspects of communication about the care transition, including what information is currently communicated between PC and oncology care, when and how the information is communicated, and what type of information is desired to enhance the quality of patient care. This study provided key stakeholder input for the development of future clinical practice changes.

Methods

Design and Participants

The current study used a qualitative, descriptive design (Sandelowski, 2000, 2010). Key stakeholders were recruited from the Choctaw Nation PC settings and the oncology care settings most frequently referred to by CNHSA using purposive sampling (Patton, 2015). Based on input from the Choctaw Nation collaborator, inclusion criteria were developed to identify healthcare team members with experience in caring for tribal patients diagnosed with cancer. PCPs, nursing staff, referral coordinators, and case managers with individuals with cancer in their caseload were eligible. In oncology settings, medical, surgical, and radiation oncologists and staff members involved in managing referrals from the Choctaw Nation (e.g., referral coordinators, intake coordinators, nurses) were eligible. All participants were aged 21–80 years, currently working in the practice setting, and living independently in the community.

FIGURE 2. Semistructured Interview Guide by Theme

Facilitators

Think of some examples where care coordination worked very well.

- What contributed to that experience?
- What type of information was received?

Barriers and Challenges

Now, think of some examples that have been more difficult to manage.

- What are the contributing factors?
- What type of information was received? Was it timely?
- What are some of the barriers that you face when trying to provide care coordinated with the oncology team/primary care team for the cancer survivors you see?

Information Sharing

- What type of information do you typically receive from the oncology team/primary care team? (Drill down to see if specific examples of the information can be described. Inquire as to the format [e.g., electronic, paper, via telephone, face to face]).
- If you were provided with some type of information from the oncology team/primary care team, did the oncology team/primary care team information provide you with any new or additional information regarding your patients?
  - If yes, was the new information related to (a) cancer/general medical history and treatment, (b) follow-up care recommendations, (c) surveillance recommendations/monitoring for chronic health conditions, or (d) long-term effects (only for primary care team)? (Try to elicit specific examples of each.)

Desired Information

- Thinking of individuals with cancer, if you could influence the type of information that is provided by the oncology team/primary care team for cancer survivors in your care, what are the key pieces of information that you need?
- At what points in the course of their cancer experience would you want the key pieces of information?
- In what format would that information be most useful to you?

Recruitment in the tribal PC setting was conducted by the Choctaw Nation collaborator. Clinic visits and telephone calls were conducted to discuss the study with potential participants. The study was explained, questions were answered, and verbal consent was obtained and documented. Verbal consent was approved for use because the research was considered to be no more than minimal risk and did not involve any procedures requiring written consent outside of the research context. No protected health information was collected; only descriptions of the processes of care coordination were collected. After documenting verbal consent, the interviewers were given contact information. During the follow-up telephone contact, two participants requested to participate by email. Oncology care practices were identified through the Contract Health Department. Practice names and locations were given to the research team, who sent an introductory letter describing the study and information about eligibility. Follow-up telephone calls ascertained interest and verbal consent. After securing verbal consent, the interviewers were given contact information.

There were 51 eligible PCP staff across all eight clinic sites. From the eligible staff, 41 consented to participate, 1 refused (no specific reason given), and 9 did not respond. Overall, 33 PCPs completed interviews: 11 physicians, 10 Contract Health staff, 9 RNs (managers, case managers, clinic nurses), 2 physician assistants, and 1 advanced practice RN.

Six of the most frequently used oncology practices were invited to participate in the study, with 73 staff eligible. Of the 61 eligible physicians, 3 declined to participate (no specific reason given), 21 agreed to participate, and 37 did not respond. Twelve nonphysician staff were contacted; all agreed to participate, and six completed interviews. Three of the most frequently used oncology practices participated, with 22 completed interviews: 16 physicians, 2 navigators, 1 nurse practitioner, 1 RN, 1 intake coordinator, and 1 front office supervisor. Data collection continued until no new information was presented in the interviews.

The University of Oklahoma Health Sciences Center Institutional Review Board and the Choctaw Nation of Oklahoma Institutional Review Board approved the study. Verbal informed consent was confirmed at the start of the interview. For the two email responses, after giving initial verbal consent to the Choctaw Nation collaborator, the consent was reviewed again during the telephone call to schedule the interview. During that call, participants requested to complete the interview by email.

Procedure and Data Collection

After informed consent was obtained, individual telephone appointments were scheduled. Interviews were conducted using a semistructured interview guide informed by the key elements of the Care Coordination Model and the current authors' Choctaw Nation partners (see Figure 2). The guide was designed to capture a rich description of the participant's role in coordinating the care of tribal patients with cancer, the perceived facilitators and challenges to care coordination, the type of information desired to provide high-quality care, and the desired information format. The interview guide was consistent across all interviews, with additional prompts used to explore individual experiences more deeply. The principal investigator (PI) completed most of the interviews (N = 47). A trained doctoral student completed six interviews. Prior to starting data collection, the doctoral student completed practice interviews with the PI, with debriefing sessions. After the doctoral student completed each participant interview, a debriefing session between the PI and the doctoral student was held to ensure the quality of the interviewing process. At the request of two participants, two PC interviews

FIGURE 3. Facilitators of Care Coordination: Selected Quotations by Theme

Primary Care Providers (N = 33)

Information shared in a timely manner (85%)

- "They will send us the office visit, which will have the orders and . . . follow-up appointment dates, times, requesting referrals, so we know where we need to get those referrals sent to, what we need to do to help the patient get the best care possible."
- "In opening up those lines of communication so that I feel like I know where in the process of the evaluation or treatment the patient is and where we're going, what the next steps are, how the patient's responding to their treatment."

Importance of the care manager/referral coordinator position (58%)

- "It seems like when you have a go-to person in each department that their focus is really for persons with cancer, it really is helpful."
- "Communication, it flows between our provider, our nurse, and then our Choctaw Referred Care person. And so, as long as we have communication . . . it usually works good."

Communication flows freely both ways (55%)

- "They kept us informed with her. We received reports back in a timely manner. . . . We didn't have to wait weeks . . . to get that. There was good communication between the facilities and, really, doctor to doctor."

Established point of contact at other site (45%)

- "For the most part, you need a good person on the other end, and I don't know if that's always a navigator per se. . . . Getting someone on a phone, at least where you can talk . . . where they have a direct line or something where you can call and ask them what they need, or if they can call you and ask you what you need. It's just conversation [with] the ones that I've had that go really well."

Oncology Providers (N = 22)

Information shared in a timely manner (77%)

- "It works out pretty well when we get referrals from providers [who have] worked with us before, so they know what we're going to be asking for, so they have the preapprovals already in place so that we can get the tests performed either before I see them or rapidly afterwards."
- "I think they do an awesome job as far as getting our referrals back in a timely manner. I can pretty much email or call or fax and get the response that I need."

Communication flows freely both ways (50%)

- "Each time I see a patient, my rule is to send my note to their provider."

Importance of the care manager/referral coordinator position (45%)

- "In Choctaw Referred Care, they have one person [who] is solely devoted to oncology. She makes sure that we have everything that we need when we are referred a patient to our practice. I have noticed that if we need something after they are here and we need a next step–type process, she is very proactive in helping us get what we need."

Established point of contact at other site (41%)

- "I have had several providers from the Native community call me directly to tell me about a patient, which is always helpful in me getting them in sooner, coordinating other testing done at their own tribal hospital before they ever come over, and then that often will also help subsequently when we're trying to get authorization for surgery."
- "We . . . have a policy that anybody that is an American Indian . . . as they come in, they have the care coordinated with the American Indian navigator team, and that team then is responsible for helping the patient navigate the complexities of our system, as well as the tribal system."

Note. Percentages are based on the number of participants who reported those themes in interviews divided by the total number of participants from the setting.

were completed by email because of scheduling conflicts. Telephone interviews were recorded and transcribed verbatim. Transcripts were verified by comparing them with the audio files. Any references to individuals by name were edited from the audio file prior to sending it for transcription. All data were collected from January 2016 through August 2017. Data were stored on a password-protected network drive that was compliant with all university requirements for research data.

Data Analyses

Conventional inductive content analysis was used to identify major themes (Hsieh & Shannon, 2005; Miles et al., 2014; Neuendorf, 2017). Data analyses were completed from December 2018 to December 2020, beginning with the PCP interviews. The coding of the interviews was completed by team members, specifically the PI and a research epidemiologist who is an enrolled citizen of a different tribe with personal and professional experience in tribal healthcare systems. Initially, each interview was read to gather an overall sense of the participant's experience. Then, the two team members conducted line-by-line coding to identify meaningful units. After coding the initial subset of interviews independently, the analysts met and reviewed each transcript. Through discussion, agreement was reached on codes and definitions for the

FIGURE 4. Challenges to Care Coordination: Selected Quotations by Theme and Subtheme

Primary Care Providers (N = 33)

Communication challenges (88%)

- Information not shared in a timely manner (100%)
  - "There is one [who] never communicates. . . . I never get a note unless I specifically have [the patient] fill out a release and call over there and get it."
  - "It's very hard . . . because the right hand doesn't know what the left hand's doing. It makes us look like we're not doing our job, when . . . our number one priority is our patients."
- No specific point of contact at other site (34%)
  - "If we did not get the fax, the patient [had] to wait, sometimes up to an hour, while we searched for a fax or called the oncologist. . . . It consumed a large amount of time for the nurse."
  - "Very hard for us because we may have to fax the referral over four, five, or six times before it ever gets to the right person."

Patient burden associated with cancer diagnosis (58%)

- Reliance on patients to transfer information (63%)
  - "Because, a lot of times, it sounds horrible to say, but they will lose those papers . . . or they forget to bring those papers in, or they forget to call us."
- Not eligible for tribal referral services (42%)
  - "If you come to us and live outside our service area, then we end up dependent on . . . Contract Health finding alternative sources for payment, because these patients don't have a payer source."
- Financial and other issues (32%)
  - "We deal with a large population that doesn't own a vehicle, or they don't have the money."

Oncology Providers (N = 22)

Communication challenges (100%)

- Incomplete, poor-quality information provided (73%)
  - "When we get a referral . . . it is usually a one-liner. . . . A lot of times, patients don't know . . . about their past history and what medications they take."
- Information not shared in a timely manner (64%)
  - "Getting authorization from the tribe to do surgery can be very difficult and time-consuming, and that leads to a delay in patient care."
- Requiring laboratory and other testing and scans be done by the tribal facility (59%)
  - "Trying to get the disc, the images, and those tests and the results . . . in a timely fashion . . . is often very challenging."
- Issues with authorizations and approvals from tribal authority (50%)
  - "For each test, we have to go through a lengthy process of preauthorization, which really gets in the way of high-quality patient care."
- No specific point of contact at other site (50%)
  - "It's difficult to find the right person at the referring office."

Patient burden associated with cancer diagnosis (58%)

- Financial and other issues (67%)
  - "Distance is a challenge, poverty is a challenge. I think distrust of the medical establishment outside their tribal system is a challenge at times."
- Reliance on patients to transfer information (53%)
  - "I normally recommend that they stay and get the blood work referral and deliver them or get their blood work done . . . and go back and pick [up the results]."

Note. Percentages are based on the number of participants who reported those themes in interviews divided by the total number of participants from the setting. Subtheme percentages reflect the number of participants from that setting who commented on that subtheme, divided by the number of participants from the setting overall who commented on the theme.

coding structure. Refinements were made through independent coding and peer debriefing discussions as the PC and oncology interviews were analyzed. Additional doctoral students were added to the team to assist with coding checks and peer debriefing sessions. Finally, the codes were examined for patterns and organized into broader themes. The findings were shared with members of the research team, including the Choctaw Nation collaborator. Initial analyses were completed using manual coding on transcripts and then shifted to computer-assisted analyses using NVivo, version 12.0.

Strategies for Enhancing Trustworthiness

Multiple strategies were used to enhance data credibility, confirmability, and dependability. Credibility refers to the extent to which findings accurately and authentically capture the participant's experience (Beck, 1993; Frambach et al., 2013; Miles et al., 2014). Participant triangulation across roles in each setting and analyst triangulation through the data analysis process enhanced credibility. Analyst triangulation minimized researcher bias and enhanced the confirmability of the findings. Notes on coding decisions were kept to document analytic decisions. Dependability, or the consistency of study methods over time and investigators, was enhanced through multiple techniques, including using a semistructured interview protocol and performing periodic coding checks (Beck, 1993; Miles et al., 2014).

Results

The themes were organized into facilitators of care coordination (see Figure 3), challenges to care coordination (see Figure 4), and suggestions for improving care coordination (see Figure 5).

Facilitators of Care Coordination

Information shared in a timely manner: In both settings, information sharing between sites was identified as a central factor in achieving the delivery of coordinated care. From the PC perspective, information from the oncology site was a key element in processing referrals beyond the initial consultation. PCPs described a desire to ensure that patients received the necessary care as quickly as possible and that everything needed prior to an appointment was addressed to avoid treatment delays. Receipt of information enabled PCPs, who typically had a long-standing relationship with the patient, to discuss visit details, address questions, and encourage follow-through. Oncology providers described the importance of receiving referrals and authorizations quickly to allow patients to be seen and a treatment plan developed. The timely exchange of information also allows for additional tests or scans to be completed before the oncology visits.

Communication flows freely both ways: Both groups noted that communication flowed easily from site to site when care coordination was working well. Providers in both settings described receiving information from the other site with updates and/or test results without needing to make multiple telephone calls or send multiple fax requests.

Established point of contact at other site: Most staff at both sites discussed the value of having an identified point of contact at the other site. This person served as a liaison and helped the other party navigate the unfamiliar system. Identification of this liaison facilitated information exchange and assistance with questions about care and/or the referral. PC staff could contact a specific person and make sure that the referral materials were complete so appointments could be scheduled. The primary role of this point of contact was to facilitate the information exchange between sites. On the oncology side, if there were questions about the referrals and authorizations, the drug formulary, or the availability of certain scans and tests, the point of contact on the tribal side could find the answers. Oncology providers also discussed the value of providing patients and PCPs with a point of contact in case of questions or concerns.

Importance of the care manager/referral coordinator position: Both clinical sites identified the care manager/referral coordinator, who oversees the referral process, as an important factor. In PC clinics, this individual was described as managing the referral process once it was initiated by the PCP. The care manager/referral coordinator gathered all required information, submitted the information to Contract Health for approval, and sent the materials and authorization to the oncology provider. Care managers/referral coordinators kept track of orders for laboratory or other testing and scans, ensured that test results were sent to the oncology provider, and maintained active referral authorizations. In oncology settings, the care manager/referral coordinator was described as a navigator for the patient and PC system; they answered questions and ensured that appropriate resources were in place. They also ensured that the necessary information for the initial consultation visit was in place prior to the visit. If anything was lacking, they worked to obtain the information prior to the appointment to minimize delays in treatment planning.

Healthcare outcomes linked to facilitators of care coordination: Both groups agreed that facilitating factors resulted in quicker appointment scheduling. The specialists had the necessary information to provide consultation and a recommended treatment plan. PCPs had the information to answer patients' questions, discuss treatment options, and encourage follow-through. Both groups described the process as collaborative care, where each provided care in their areas of expertise, working together to provide the highest quality of care.

Challenges to Care Coordination

All oncology participants and most PC participants reported challenges associated with communication between sites.

No specific point of contact at other site: The lack of an identified point person was an issue. Without knowing who to contact, there was no guarantee that the faxes were seen by the right person to keep care processes moving forward. Making telephone calls was a challenge without a specific contact.

Information not shared in a timely manner: PCPs found it difficult to answer patients' questions without progress notes or treatment plans in the medical record. Patients often sought out their providers to discuss their care because there was an existing patient–provider relationship. Tribal staff expressed frustration about the lack of information, in part because it gave the appearance that the provider was not knowledgeable and/or the tribal healthcare system was somehow inadequate. From the oncology providers' perspective, many timeliness issues were associated with obtaining authorizations from the tribal system. Information sharing was described as

FIGURE 5. Suggestions to Enhance Care Coordination: Selected Quotations by Theme

Primary Care Providers (N = 33)

Expressed desire to receive treatment plan that includes diagnosis, prognosis, and plans for treatment (82%)

- "We'll be expecting a detailed assessment of what's [going to] start, when the start date is, and what's projected . . . if there's any test results that need to be done during that time . . . make sure we have all of those ahead of time."

Regular updates (52%)

- "One thing that might make it easier . . . on everybody is maybe if they had . . . a cheat sheet for each. . . . 'This is the medicine they are on . . . the side effects to watch out for . . . some thoughts about treatment for side effects.' . . . I would like to know . . . what to be observing for recurrence or maintenance."

Recommendations for surveillance of disease and survivorship from oncology provider (33%)

- "A summary of care at the end of the treatment with any recommendations or continued follow-up or what things need to be looked at for the long term"

Established point of contact at other site (27%)

- "If you have one person . . . and you have pretty good communication with them, I've found that really helps."

Expressed interest in improved patient education (18%)

- "Sometimes they talk in a different language at the oncology office."

Improved, timely communication (33%)

- "Send those office notes or [laboratory] orders, or anything like that—just fax that directly to us instead of us having to wait for the patient to . . . bring that in."

Oncology Providers (N = 22)

Improved communication (41%)

- "What is the expectation of the primary care doctor from me or my clinic or what I want from the primary care physician? I think that communication can get better."
- "If we had some way of electronically sharing the information back and forth and messaging people quickly with 'We're going to need the following authorizations quickly,' or 'This has just changed,' or 'The patient has diabetes and hypertension, and we need things much more tightly controlled within 10 days because we're about to have an operation.'"

Ability to have laboratory and other tests done at the oncology site instead of at the tribal site (27%)

- "I just feel like that's a tremendous limitation, and if they're going to send their patients to us to take care of them, then we need to be able to take care of them the best that we possibly can, and that includes ordering and reviewing ancillary tests."
- "I would rather it be done here. That way, we're not tracking down results, postponing care."

Survivorship care plan (27%)

- "I don't have standard printed information for that. . . . It probably would be a nice thing to put together."
- "Our goal is in moving forward to have more source material that gets to the patient so that they feel comfortable and they know what their plan is. . . . It is verbalized, but I don't think it is written like it should be."

Note. Percentages are based on the number of participants who reported those themes in interviews divided by the total number of participants from the setting.

burdensome, such that only periodic updates were sent to PC, rather than an update after each visit. Contributing to the burden was the electronic health record (EHR) system and its inability to automatically send updates to the referring provider.

Issues with authorizations and approvals from tribal authority: Those in the oncology setting identified several additional communication challenges, including the requirement that laboratory or other testing and scans be done at tribal facilities. Tests and scans that are ordered by oncology providers must be preauthorized if performed at a nontribal facility. About half of the oncology providers described authorization issues.

Incomplete, poor-quality information provided: Almost two-thirds of the oncology providers expressed difficulties with the information they received with a referral request, such as missing test results or images or having limited information on the patient's history, current medications, and reason for referral. Some identified an issue with the EHR, describing how outside documents are scanned and placed into a section of the chart that is unsearchable and contains no indexing.

Requiring laboratory and other testing and scans be done by the tribal facility: Another unique challenge faced by those in the oncology setting is the requirement that laboratory and other testing and scans that can be done by the tribal healthcare system must be done by the tribal system. These images may not be at the needed angles or sharp enough to make diagnostic decisions. According to the providers, staff at oncology sites are trained to provide the images needed, whereas tribal healthcare staff complete specialized scans infrequently.

More than half of the participants in each group identified patient burden as a challenge. Most identified issues related to the partnering of two distinct healthcare systems and to financial concerns.

Reliance on patients to transfer information: Providers at both sites discussed that patients often act as the couriers between those sites. Patients were asked to take films, discs with images, laboratory results, and authorization paperwork to the oncology site. Once the oncology visit was completed, patients were asked to take a visit summary and orders needed prior to the next visit to the PC site.

Not eligible for tribal referral services: One of the more common challenges was linked to the eligibility criteria for referred care services. When patients required cancer specialty care and did not meet the eligibility criteria (e.g., living within the service area), PC staff had to try to identify other payment options.

Financial and other issues: Both groups discussed issues associated with the travel required for specialty care. Patients incurred costs associated with finding transportation; paying for gas; and securing a driver, food, and lodging. Family members serving as drivers frequently had to take time off of work.

Healthcare outcomes linked to care coordination: Both groups described that these challenges led to delays in patient care and treatment that might result in adverse events. Another common outcome was the significant staff time needed to gather information from the other site. Difficulties in information gathering contributed to delays in patient care and resulted in both groups expressing frustration at not being able to provide high-quality care. The PC group shared that poor communication can result in patients getting laboratory and other testing and scans done at the oncology site, leading to patients bearing the costs if they were not authorized. From the oncology perspective, the challenges in exchanging information affect treatment decisions, and patients may get frustrated and disappear.

Suggestions to Enhance Care Coordination

Both provider groups offered suggestions to improve care coordination. The groups focused on varied strategies that would enhance communication between the practice sites. PCPs suggested receiving detailed information on the treatment plan, including diagnosis, prognosis, and specific information about the type(s) of treatment (e.g., surgery, chemotherapy, radiation therapy).

PCPs discussed the importance of receiving regular updates from the oncology team during active treatment. Detailed progress notes and information about the medications and potential side effects were frequently mentioned. PCPs valued receiving recommendations about surveillance as patients completed their cancer treatment. Receiving this information from the oncology practice in a timely manner was suggested. Most PC staff defined "timely" as being within a couple of days to a week. Ideally, the information would be sent automatically by the oncology team. One suggested strategy to enhance communication between the two systems was to identify a specific person who was knowledgeable about referrals and could serve as a point of contact at each oncology practice.

Enhanced patient education was also identified for improvements. PC staff discussed the importance of making sure that patients understood how tribal referrals worked, as well as the rules and limitations for receiving care. Staff described existing processes but suggested that additional repeated efforts were needed. Another recommendation was to provide some basic education on cancer care and what to expect, as well as questions to consider asking, in preparation for the oncology visit.

Oncology providers discussed the importance of improved communication. Providers desired clear communication so that expectations were clear. Another recommendation was to ensure that the EHR facilitated information sharing, with the longer-term vision of providers in the two settings being able to view information reciprocally. Oncology providers identified the ability to order specific scans and tests and have them completed at the oncology site as important in improving the quality of patient care and enhancing coordination. Improved quality of images and shortened turnaround time were two reasons offered in support of this recommendation. Oncology staff are more likely to have obtained the needed images for a given cancer site than the PC staff. Providers are on staff and can also read the images and review test results more quickly.

All oncology sites described survivorship care plans as a work in progress. The development of written materials that could be given to and reviewed with patients would be an important step. The survivorship care plan would provide a written document that could be reviewed, in contrast to the current verbal discussion.

Discussion

Key findings highlighted the central role of communication in effective care coordination for individuals with cancer across three subdomains: ease of communication, information being communicated, and system and method of communication. Improving communication requires enhancing the process across all three subdomains. PCPs and oncology providers valued the timely exchange of information. Timeliness was described as having the information needed when the patient was being seen for care. Both groups described the importance of communication that flows between clinical sites. The Agency for Healthcare Research and Quality includes the exchange of information as part of its definition of care coordination (Sada et al., 2011). Findings from the current study regarding the central role of oncology provider–PCP communication are consistent with earlier work (Agency for Healthcare Research and Quality, 2018; Brouwers et al., 2016; Flieger et al., 2019; Gorin et al., 2017; Haynes et al., 2018; Hershey & Given, 2020; Klabunde et al., 2013; Mayer et al., 2017; Nekhlyudov et al., 2017; Overholser & Callaway, 2019; Rubinstein et al., 2017; Uijen et al., 2012; Walsh et al., 2011; Weaver & Jacobsen, 2018). In the clinical setting, participants shared that having a specific person identified at each site helped facilitate the exchange of information. Other studies have reported that having personnel identified to manage information sharing was key to effective care coordination (de Witt et al., 2020; Mason et al., 2013). PCPs recommended receiving regular updates along with the treatment plan to enhance care coordination. Ideally, survivorship care plans at the completion of treatment would provide details about surveillance and potential long-term side effects. In the current study, PCPs focused on the information needed rather than a specific format for the information. Several studies demonstrated an increase in collaboration between oncology providers and PCPs when information was exchanged (Dossett et al., 2017; LaGrandeur et al., 2018; Mason et al., 2013; Uijen et al., 2012).

Several challenges to care coordination emerged from the interviews. PCPs described not receiving information in a timely manner as a key challenge. In addition, PCPs were unable to answer patient questions because of the lack of information. PCPs shared that patients were expected to bring information back to their PCP after the oncology visit, including orders and any updates to the treatment plan. Patients often would lose the documents or forget to bring them to the clinic. The difficulties with relying on patients to play a central role in information exchange are consistent with findings in earlier studies (Brouwers et al., 2016; Hohmann et al., 2020; Mayer et al., 2017).

Oncology providers described challenges with getting the necessary information for consultations or laboratory and other testing and scans from the tribal site in time to make treatment decisions. Federal policies for IHS-supported sites require in-house testing to be completed where available. A central component of care coordination is the communication of test results when completed by the tribal health site. About half of the oncology providers in the current study described difficulties with getting tribal authorizations for care, which often led to canceled visits, requiring rescheduling. Both groups identified the travel to oncology care as a challenge, along with the associated financial burden linked with travel.

In a systematic review, Gorin et al. (2017) found that effective care coordination was characterized by navigation services for patients and nurse case management. For PCPs and patients, the navigator and/

or nurse case manager may serve as that point of contact for information, questions, and resources to address financial issues, concerns about transportation, lodging, and other needs (Dossett et al., 2017). Research has reported that a designated care coordinator facilitated communication between practice settings, monitored patients for ongoing psychosocial needs, and provided linkages to available community services (Lisy et al., 2021). The navigator or nurse case manager may serve as the linkage between PC and oncology care (Agency for Healthcare Research and Quality, 2018; Chaput & Sussman, 2019; Haynes et al., 2018).

Geographic isolation, medical mistrust, and cultural dissonance have led to poor cancer-related health outcomes in AI/AN individuals. Decreased health service accessibility and, consequently, cancer screening has resulted in later-stage cancer diagnosis, delayed treatment, and increased cancer-related mortality rates among these populations (Adams et al., 2017; Goodwin et al., 2017; Guadagnolo et al., 2017; Jerome-D'Emilia et al., 2019). Consistent with the literature, geographic isolation and decreased health service accessibility negatively affected continuity of care in the current study. The average age of IHS hospitals is 40 years, which is 10 times the average age of other hospitals in the United States. These facilities are also often understaffed and undersized, compromising quality of care (IHS, 2016b).

Although efforts have been made to alleviate staffing challenges in tribal healthcare facilities, limitations in the ability to offer competitive salaries, the rural nature of many tribal health facilities, restrictive federal hiring policies, and limited capacity to support residencies and fellowships contribute to substantial workforce shortages and long-term medical leadership vacancies (IHS, 2016a). Given the overlap in challenges between IHS facilities and, in some regards, the Choctaw Nation Health System, hiring additional staff to ameliorate clinical discrepancies is not always feasible. These nuanced challenges of clinical staff recruitment and retention in the tribal health context, including mid-level providers and patient navigators, may limit opportunities to implement interventions related to cancer care coordination.

Limitations

This study had several limitations. Data are from one tribal healthcare system located in rural Oklahoma. Other rural PC practices may not experience similar challenges with coordinating cancer care, particularly if they are part of the larger healthcare system with integrated EHRs. Conducting single interviews with participants in both settings did not allow for member checking (i.e., when investigators take findings back to participants for feedback regarding the results) as analyses were completed. However, a variety of providers were interviewed. The diversity in roles maximized the information obtained about cancer care coordination from both perspectives. Collecting data from two providers by email may have limited their responses; however, the authors followed up with questions to clarify or amplify the responses. Patient perspectives are not reported. However, a separate article describing patient views is in progress.

KNOWLEDGE TRANSLATION

- Enhanced communication between primary care and oncology providers may improve the quality of care for individuals with cancer and the care delivery process for tribal individuals with cancer.
- Nurse case managers, based at both the oncology and tribal healthcare sites, may enhance care coordination through effective facilitation of communication and information exchange between primary care and oncology providers.
- Future research must focus on evaluating specific strategies to enhance cancer care coordination for patients receiving primary care in a tribal healthcare setting and referring patients to oncology specialists.

Implications for Nursing

The results of this study provide the Choctaw Nation Health System with important information for enhancing patient-centered care for individuals with cancer and provide support for the role of the cancer nurse case manager to coordinate the care of tribal individuals with cancer. In the tribal healthcare system, with inherent complexities because of its reliance on out-of-system oncology care, nurse case managers could be the keystone in enhancing communication between practice sites. Managing the referral process, tracking the exchange of information between practices, and ensuring that patients have the necessary information and resources may lead to improved cancer outcomes in this high-need population. Tribal nurse case managers can prepare patients for their oncology appointments in terms of what to expect and what questions to ask. Working with their oncology counterparts, tribal nurse case managers can actively intervene to obtain clinical data needed to complete a survivorship care plan. Elements of this study's implications may be transferrable to other rural tribal health settings. However, historical, cultural, socioecological, and health system infrastructure contexts must be considered prior to implementation. Consistent with the literature, the current authors found the oncology patient navigator role in this study to be expansive and to often extend beyond patient needs to provide care coordination support to other medical staff. However, the role of patient navigators in other health settings varies greatly and is largely dependent on clinical and patient needs (Cantril et al., 2019; LaRosa et al., 2019). Patient navigation programs have been shown to improve referral times (Chavarri-Guerra et al., 2019), provide support across the cancer continuum, and seek to increase access to care (Braun et al., 2012). Patient preferences regarding navigator roles, responsibilities, and required training are influenced by many factors, including age and distance from oncology site (Pannier et al., 2019; Warner et al., 2018). Importantly, the findings of the current study illustrate the contrast between the roles of navigators in the PC and oncology settings. Although oncology patient navigators aid in patient logistics, such as referral coordination, PC navigators provide support in regard to patient education, survivorship care plan development, and social determinants of health. This contrast in patient navigator roles, clinical strategies, and patient needs illustrates the importance of cultural and community tailoring. Future research should evaluate the cancer nurse case manager in the tribal setting to assess the impact on timely information exchange and patient outcomes.

Conclusion

Evidence for best practices to coordinate cancer care for patients from rural locations or tribal healthcare systems is limited (Haynes et al., 2018). Facilitating communication between PCPs and oncology providers is critical. Potential care improvement interventions must address the ease of communicating between sites, the specific information shared between sites, and the structure and method of communication.

When patients are referred to another healthcare system for oncology care, developing strategies to eliminate barriers to information exchange is critically important. The designation of a specific person to coordinate care in both settings may enhance the communication processes between settings and link patients to resources. Future research must focus on evaluating specific strategies to enhance cancer care coordination for patients receiving PC in a tribal healthcare setting.

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