

Qualitative analysis of cancer care experiences among rural cancer survivors and caregivers

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Abstract

Purpose: Rural (vs urban) patients experience poorer cancer outcomes and are less likely to be engaged in cancer prevention, such as screening. As part of a community needs assessment, we explored rural cancer survivors' and caregivers' experiences, perceptions, and attitudes toward cancer care services.

Methods: We conducted 3 focus groups (N = 20) in Spring 2021 in rural Nebraska.

Findings: Three patterns of cancer diagnosis were regular care/screening without noticeable symptoms, treatment for symptoms not initially identified as cancer related, and symptom self-identification. Most participants, regardless of how diagnosis was made, had positive experiences with timely referral for testing (imaging and biopsy) and specialist care. Physician interpersonal skills set the tone for patient-provider communication, which colored the perception of overall care. Participants with physicians and care teams that were perceived as "considerate," "compassionate," and "caring" had positive experiences. Participants identified specific obstacles to care, including financial barriers, transportation, and lack of support groups, as well as more general cultural barriers. Survivors and caregivers identified organization-based supports that helped them address such barriers.

Conclusions: Rural populations have unique perspectives about cancer care. Our results are being used by the state cancer coalition, state cancer control program, and the National Cancer Institute-designated cancer center to prioritize outreach and interventions aimed to reduce rural cancer disparities, such as revitalizing lay cancer navigator programs, conducting webinars for primary care and cancer specialty providers to discuss these findings and identify potential interventions, and collaborating with national and regional cancer support organizations to expand reach in rural communities.

KEYWORDS

cancer care, cancer prevention, focus group, qualitative analysis, rural health

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BACKGROUND

In the United States, rural residents have less access to specialized health care compared to their urban counterparts.¹⁻³ The rural health care system is spread out and has fewer specialists, including oncologists, radiologists, pathologists, surgeons, and radiation oncologists.³ Facilities and services essential for cancer treatment, such as laboratories and radiation therapy, are also more sparse in rural areas.³ Therefore, rural residents often need to travel long distances to obtain cancer screening, diagnosis, and treatment.²⁻⁸ Rural patients' access to care is further aggravated by low socioeconomic status, lack of insurance coverage,⁸ weather-associated road conditions, and lack of public transportation.⁷ These rural-urban differences lead to disparities in the utilization of cancer screening services as well as the use of adjuvant therapy.⁸

Differential access and utilization of cancer-related services are important metrics due to their association with negative cancer outcomes. For example, lack of access to care is associated with later stage diagnosis,^{2,3,9} higher incidence and mortality rates,^{10,11} and poorer survival¹²⁻¹⁴ among rural versus urban residents. A national study found that incidence rates of lung, cervical, and colorectal cancer were significantly higher among rural versus urban residents, and the incidence rate for human papillomavirus-related cancers in rural communities increased between 1995 and 2013.¹⁵ Further, a recent study indicated that rural Medicare recipients with cancer had worse health-related quality of life compared to urban counterparts.¹⁶

Diagnosis and treatment experience is unique to cancer patients, necessitating qualitative research to understand their perspectives.¹⁷ Previous rural focus group studies of cancer care and survivorship were conducted mostly in the Southern region of the United States or focused on African American or Hispanic residents.¹⁸⁻²¹ Nebraska is a predominantly White, mostly rural state; of the 93 counties, 48 are classified as rural and 31 as frontier (fewer than 7 residents per square mile).²² The 12 cancer centers accredited by the American College of Surgeons Commission on Cancer, located in counties classified as 2-5 on the Rural-Urban Continuum Code (RUCC), are affiliated with the Nebraska Cancer Coalition (NC2).²³ As part of a state-wide cancer needs assessment, the University of Nebraska Medical Center (UNMC) collaborated with NC2, Nebraska Comprehensive Cancer Control Program (NECCCP), and 4 cancer centers to conduct focus groups with rural cancer survivors and caregivers. The overall purpose of the study was to explore the perceptions of rural residents on their cancer experience. Specifically, our research questions were: (1) What is the overall community health status perceived by cancer survivors and caregivers? (2) What are sources of information for cancer and cancer prevention in rural communities? (3) What was the experience (positive and negative) of rural cancer survivors and their caregivers during diagnosis and treatment? and (4) What were the barriers to receiving cancer care?

METHODS

This qualitative study used a collective case study design, in which multiple cases (ie, rural cancer centers) were used to produce a more com-

prehensive understanding of a specific issue (ie, rural residents' cancer experiences).²⁴ Data were collected through focus groups to put participants at ease, generate discussion on the topic, and minimize costs.²⁵ Survivors and caregivers were included in the same groups to ensure a sufficient number of participants from each center and to address cost and time constraints. The study was deemed exempt by the UNMC Institutional Review Board.

Research team qualifications

The all-female research team was led by doctoral-level epidemiologists (KLR and SWG) with experience in cancer research. Other team members included public health students (JR and KN), a community outreach program coordinator (LL), a qualitative researcher (DD), and 2 cancer program administrators (TR and LS). Focus group roles included facilitation (KLR), Zoom polling (JR and LL), and notetaking (SWG, LL, and KN). Two practice sessions were conducted with public health students prior to initiating data collection.

Participants and recruitment

Cancer centers were located in central and western Nebraska counties classified 3-5 on the RUCC, with city populations ranging from 25,000 to 51,000. Although counties classified as "3" are considered metropolitan counties, the selected cancer centers serve patients from a wide geographical range, with some patients traveling an hour or more to receive care. The NC2 program director facilitated introductions between contacts at multiple rural-serving cancer centers and the researchers and helped set up informational meetings to introduce the project.

We asked the cancer centers to distribute the recruitment flyer, which stated the purpose, topics, compensation (\$40 gift card), and eligibility criteria (30 years and older, cancer patient/survivor or caregiver, and Nebraska resident). We used age 30 years to focus on adult (rather than pediatric) cancer although we did not limit caregiving to adult-onset cancers. The flyer contained a phone number and email address for interested individuals to contact the research team; later versions of the flyer also included a web address and QR code to the REDCap screening survey. The survey included questions to confirm eligibility, contact information, and general availability. A researcher contacted potential participants to schedule the focus groups and to offer Zoom practice sessions for those unfamiliar with the technology.

Setting, format, and procedure

Due to COVID-19 restrictions, the groups were held virtually via Zoom, a cloud-based video conferencing platform that can be used with computer, free mobile app, or phone-based call-in.²⁶ The Zoom polling feature enables prebuilt questions to appear on-screen with point-and-click participant responses. Polls were used to anonymously collect a

TABLE 1 Facilitation guide questions and initial coding schemes

Guide sections and questions	Initial coding themes
Community health status	
Poll: Overall, how would you rate the health status of your community?	Health status
Poll: Overall, how important is cancer (of any type) a health concern in your community?	Health concern
Cancer experiences	
How did you or your loved one find out you or your loved one had cancer?	Cancer diagnosis
What positive experiences or challenges did you have with cancer treatment?	Positive experiences Negative experiences
Poll: Think back to the time before your cancer diagnosis. Where did you get information about cancer or cancer prevention?	Information sources
Poll: Of the various sources of information available about cancer and cancer prevention, which source do you trust the most?	Trusted information
When you were diagnosed or began treatment, where did you go to learn about cancer diagnosis and treatment?	Where to go for services
Wrap-up	
What are some of the challenges, barriers, and needs people in your community face when dealing with cancer (of any type)?	Barriers

limited amount of quantitative data as introductions to discussion topics. Three 75- to 90-minute groups were conducted between February 26 and May 28, 2021 with 6-8 participants per group. Sessions were audio and video recorded.

University researchers met with NC2 and NECCP to set the study scope. Following review of the overall needs assessment research questions, focus group questions were formulated based on a community health needs assessment²⁷ and published literature²⁸⁻³² and placed into thematic categories by JR with review by KLR and SWG. NC2, NECCCP, and participating cancer centers reviewed the guide and provided feedback before it was finalized. The guide included an introduction, community health status, cancer experiences (diagnosis and treatment, sources of cancer-related information), colorectal cancer screening (reported elsewhere), and wrap-up (Table 1). Built-in polls were interspersed with open-ended discussion questions. Prompting and probing questions were built into the guide for each topic and some questions were marked “time permitting.”

Coding and analysis

Verbatim transcripts were created by a third-party professional transcription service and checked for accuracy by the researchers. Data were manually analyzed in Word documents using directed content analysis.³³ Following the first session, SWG deductively developed broad codes from the guide and reviewed them with KLR. Independently, KLR and SWG read the transcript before inductively coding sub-themes. They compared and reconciled any discrepancies, expanding and contracting some categories. After reaching consensus, a codebook was developed and brought to the research team for feedback. This initial codebook served as the basis for iteratively coding the

remaining transcripts, adding subthemes when content did not fit and ensuring data saturation. To ensure data validity and trustworthiness, several steps were followed.³⁴⁻³⁶ For credibility, investigator triangulation was utilized by having 2 primary reviewers handle initial coding and analysis with further checks by 3 additional researchers. A detailed description of the data collection and results was provided to DD for further review. For dependability and confirmability, an audit trail was maintained as records of each step of the research process were kept as meeting notes and via editing software (track changes and comments) in Word documents saved to a shared file repository, which tracks document edits. Finally, to provide transferability, thick description was utilized to provide context of the findings.³⁴⁻³⁶

RESULTS

Twenty-seven individuals registered to participate. A physician who tested the system before sharing recruitment fliers was excluded, 3 individuals were unresponsive to multiple contact attempts, 1 had a scheduling conflict, and 2 did not attend, resulting in 20 participants (16 survivors, 5 caregivers, with 1 participant identifying as both survivor and caregiver). Two groups included spousal survivor-caregiver dyads. Represented types of cancer included: breast, lung, bladder, multiple myeloma, lymphoma, and prostate (Table 2).

Community health status

In polling, participants rated their community health status as very good (44%) or excellent (11%), with only 1 participant selecting a nonfavorable response (Figure 1); 90% indicated that cancer is a

TABLE 2 Participant characteristics

Characteristic	Total (n = 20)	FG #1 (n = 8)	FG #2 (n = 6)	FG #3 (n = 6)
Gender				
Female	16	7	5	4
Male	4	1	1	2
Role ^a				
Patient/survivor	16	7	5	4
Caregiver	5	2	1	2
Cancer type ^a				
Breast	11	7	1	3
Lung	2	1	1	
Bladder	1	1		
Multiple myeloma	2		2	
Lymphoma	2		1	1
Prostate	1			1
Estimated travel time ^{a,b}				
Local (<15 minutes)	12	6	1	5
Nearby community (15 to <30 minutes)	1	1		
30-60 minutes	5	1	3	1
>1 to <2 hours	0			
2-2.5 hours	2		2	
>2.5 to <4 hours	0			
4 hours	1			1

^aParticipants could indicate multiple responses (multiple roles, cancer types, and providers).

^bFor participants who did not directly provide estimated travel time to care, it was estimated using Google Maps from the centroid of the residential city to the care location(s) indicated. Travel information was not available for all caregiver situations.

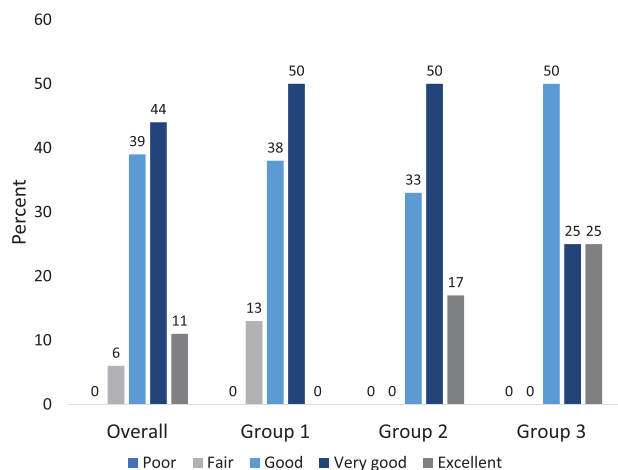


FIGURE 1 Community health status

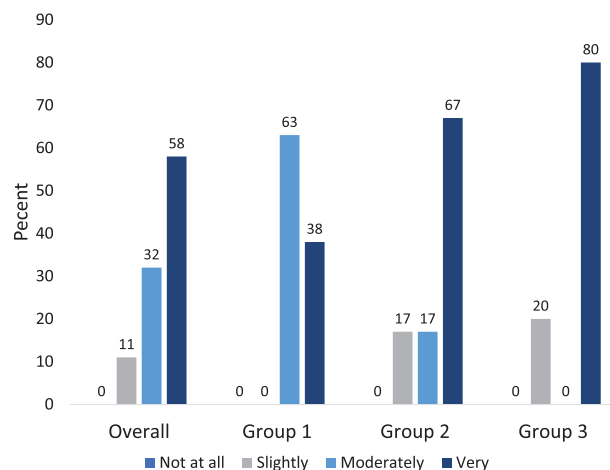


FIGURE 2 Importance of cancer as a community health concern

moderately or very important community health concern (Figure 2). Discussion themes included: sources of cancer information, cancer diagnosis, care coordination, patient-provider communication, barriers, and supports.

Sources of cancer information

In polling, the most common sources of information about cancer or cancer prevention included health care provider, family member or friend, and the internet (Figure 3). Participants relied on materials provided by physicians, the cancer center, and people who were going

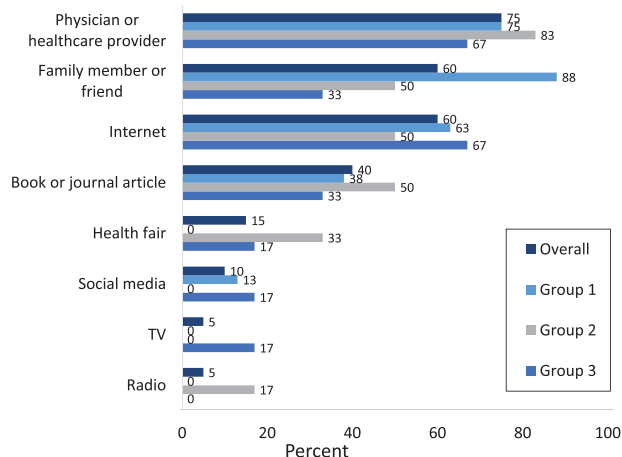


FIGURE 3 Sources of information about cancer and cancer prevention.

Note for Figure 3: Respondents could select multiple answers

through a similar experience. Internet involved search engines, such as Google. All but 1 participant indicated that physician was the most trusted source of information; the other trusted source was the spousal caregiver.

Cancer diagnosis

We identified 3 general patterns of cancer diagnosis: regular care/screening without noticeable symptoms, treatment for symptoms not initially identified as being cancer related, and self-identification of symptoms. Approximately half of the experiences with cancer diagnosis were the result of routine annual care or screening (breast cancer and prostate cancer), exemplified by a female breast cancer survivor's experience: "I went in for my yearly mammogram... They felt and saw on the CT scan something that shouldn't have been there and so I went in and had a biopsy done." Another participant in the same group followed up with "Yeah, it was very similar for me, too. I went in for my yearly checkup and the doctor felt something and he said you need a mammogram." These participants received timely referral for follow-up diagnostic testing, notification of results, and referral to cancer specialists for treatment. One participant mentioned annual postcards from the mammography center. When she did not get the reminder, she asked her primary care provider (PCP), who told her the service had switched to the hospital; the PCP connected her to the new location. Another participant said she had not received a mammogram for several years until she switched to a new PCP who "just insisted... that I go and it was a good thing because that was when I was diagnosed" with metastatic breast cancer.

Six individuals received care for symptoms not suspected as cancer; time from symptom presentation to cancer diagnosis ranged from weeks to more than a year. For example, a female bladder cancer survivor "ended up in the hospital with sepsis... from a UTI and I had gone to the doctor the week before and told them I had a UTI and he said no,

everything is clear. Well, we discovered it wasn't." A caregiver reported that her husband "was sick for a year and we kept going to different specialists, having different tests done, couldn't find anything and it was at the end of the year when our [PCP] said we hadn't done a chest x-ray and Bingo, it lit up" revealing advanced lung cancer. A survivor reported being "misdiagnosed" for 2¹/₂ months related to stomach pain before being referred for a bone marrow biopsy and diagnosed with multiple myeloma. A participant with osteoporosis had been seeing a physical therapist regarding her rotator cuff. The therapist recommended she see an osteoporosis specialist, who "picked up on some abnormalities in my lab values and he did more testing and then he called me and said you need to get a referral to a hematologist right away." She was diagnosed with multiple myeloma within a month.

The remainder of the represented cancer cases were "self-diagnosed" by noticing a lump or pain; many but not all of these were female breast cancer. "I just found it myself and then went to see the general practice doctor and she said it seemed abnormal so she sent me for an ultrasound and biopsy." A male lymphoma survivor went to his PCP for "a lump on my throat" and was told to "wait a couple of weeks and it might go away and it might be... a cold or something... I went back a couple of weeks later and it was still there." Participants reported waiting anywhere from 1 to 4 weeks to see if the symptoms resolved before seeing a physician. For example, 1 survivor previously had a benign brain tumor that caused her to be more attentive to her body. She noticed a site in her mouth that started growing and was eventually diagnosed with mucosa-associated lymphoid tissue lymphoma.

Care coordination

Most participants, regardless of how the diagnosis was initially made, had positive experiences with timely referral for testing (imaging and biopsy) and specialist care. Most received biopsy results within a few days; some took up to 2 weeks. Notification method varied by health care provider, with some scheduling in-person visits and others having the doctor or nurse call the patient. Some participants found phone notification acceptable, and others preferred in-person notification.

The PCP or hospital often scheduled the initial specialist appointment. One patient said the initial appointment was at a center far from his residence, so he asked the provider to transfer care to a closer cancer center. A survivor reported that her PCP "immediately got in touch with the specialist... and they were working together." Once patients were working with a cancer center, care was often coordinated by a nurse navigator. As 1 survivor stated, "my care was coordinated, and it is still being coordinated now that I am in maintenance phase." Participants also described referrals to support services as part of their care coordination.

However, not all participants had positive experiences with care coordination. A female breast cancer survivor from an outlying community reported numerous problems. At age 37, she experienced pain "like mastitis" so she went to the local hospital and saw an on-call doctor because "my doctor was out." She was told "you don't have any

reason to have cancer, but I want to get a mammogram and an ultrasound just to be safe.” The doctor then referred her for biopsy while downplaying the possibility of cancer: “She gave me all of the other scenarios except for you know, if left in, it could be cancer...After the biopsy, they said if after 7 to 10 days if you don’t hear anything, give us a call back.” After 11 or 12 days, the patient had not received the test results but did not know which provider (biopsy provider, PCP, or on-call provider) to call. After multiple calls, the referring doctor “called me and she apologized up and down because lo and behold the test results had been sitting there; they had them for over a week, but somewhere I got dropped.” This survivor’s negative experience with care coordination continued into treatment because she did not receive explanations about next steps or what to expect. She reported confusion about the order in which she was scheduled to see specialists (surgeon was scheduled before oncologist).

Another survivor reported a similar experience with delayed notification and confusion about which doctor to contact. She repeatedly called her provider trying to get the biopsy results. Eventually, the nurse called back and “told me over the phone [that it was cancer]...It was hard to get that news over the telephone...So I had that news and I had to drive [an hour] home [from work]” with the emotional burden of the diagnosis. One caregiver highlighted the need to consider the psychological impact of cancer diagnosis when she suggested.

“In an ideal world, there is a psychologist sitting down the hallway whenever somebody comes in and gets that diagnosis. If they could just stop in for ten minutes and say ‘Hey, do you want to do a follow up appointment?’ or ‘I am just going to pop my head in once in a while’ and just let that casual conversation happen.”

Another aspect of care coordination related to provider preparedness. A survivor was frustrated that the specialist “hadn’t read through the report fully” and “fumbled through all the papers...and the nurse knew more about it than [the physician].” Another participant stated that the doctor was unaware of the treatment plan. Other participants noted the difficulty of rural cancer centers retaining specialists, referring to the turn-over as “radiation oncologist of the month.”

Patient-provider communication

Participants reported that the physician’s interpersonal skills set the tone for patient-provider communication, which colored the perception of overall care. Participants who worked with physicians and care teams they perceived as “considerate,” “compassionate,” and “caring” had positive experiences. As 1 survivor explained, “they just showed me such care and concern. I mean, I was connected with everybody.” Participants who reported positive experiences described receiving adequate information, being allowed to ask questions, and having options. Shared decision making was reflected in statements, such as “I have received the information I’ve needed and am always encouraged to ask questions” and “[doctor] kept us all involved and never rushed those kinds of things.” One survivor described interrupting the oncologist and asking him to “start at the beginning” because he assumed that she knew more than she did; he apologized and started over. Several

participants described making treatment decisions (eg, local vs radical surgery) based on survival information provided by the physician. A prostate cancer survivor noted, “I had four options,” the physician discussed the pros and cons of each, and he decided based on survival rates.

In contrast, other patients and caregivers reported negative care experiences. These participants perceived the physician as “proud” or “lacks just any sort of compassion, understanding, caring, human interaction, is strictly all business.” In such situations, several participants reported getting a second (or third) opinion even if it meant additional travel, but not all felt like they had options about providers. One survivor noted her only negative interaction was with a physician who was “a very good doctor but not very personable, and I think he thought he was a little God.” Several participants in the group agreed with that assessment of the doctor’s interpersonal skills. Another survivor related that an oncologist “called me a crybaby. He yelled at my husband in the office.” Another described her physician as aggressive, demeaning, and “in my face.” Participants described not being allowed to ask questions and not receiving adequate information. Another survivor described a surgeon’s explanations as “overwhelming” to her and went on to state that the surgeon “had no desire to listen to what I was telling him, and I did not have a good experience with my surgeon...[He] thought he knew it all...was just really rude.” He downplayed her mastectomy by saying “It’s just a breast...it’s no big deal.” She went on to say that she wished there was a way to “talk to doctors and just tell them what it feels like, especially that first diagnosis. I don’t think they always realize how traumatic it is.”

Barriers to care

Participants identified specific obstacles to care, including financial barriers, transportation, and lack of support groups, as well as more general cultural barriers. Financial barriers included insurance deductibles and high cost of medications. “The financial piece and insurance and deductibles and just constant, you know, debt and not really feeling like there is a sense of being able to crawl out of it.” Another participant said, “Thank God I’m on Medicare and have good insurance. Otherwise, I don’t know how people do it, at \$50,000 every three weeks.” One survivor indicated that she lost her insurance early in her cancer journey. Transportation was a burden in terms of time and money for several participants (“gas was quite costly”), particularly those in outlying communities who traveled an hour or more for care. Participants indicated a need for cancer support groups dealing with types of cancer other than breast cancer, for patients as well as caregivers/family, and in more geographical locations. “I remember when my dad had lung cancer, being somewhat frustrated because I was trying to find a support group for lung cancer family, as well as for him, and there wasn’t anything in our area and at that time there was a lot of breast cancer stuff.” A patient from an outlying community was unaware of any local support groups that he could attend.

Several participants also mentioned cultural barriers. One participant stated, “our different cultures and our different language is a

big roadblock.” Another participant commented that it was not sufficient to focus on bilingual materials because “If you put for English language and then Spanish, then do you also have to put for Somali and Sudanese and Vietnamese and all of those?” In addition to language barriers, participants noted cultural differences in seeking medical care. They identified the need for more bilingual PCP, free or low-cost primary care clinics (even if offered on a limited basis), and a need for community education (suggested to work through religious organizations) about the importance of receiving regular health care as well as cancer-specific education among residents from diverse cultural backgrounds.

Organizational and social support

Survivors and caregivers identified organization-based supports that helped them address barriers to care. Being referred to and receiving supportive services from the cancer centers was valued by participants, although some expressed a reluctance to fully utilize such services, characterized by “It just seems like I’m always asking for help.” Another participant expressed gratitude about being reminded that support services are there if you need them. Support organizations included the cancer centers, local foundations, organizations that helped fundraise to cover treatment-related costs, and pharmacies. The “full-time social worker [was] really great on trying to find assistance with gas cards.” Others noted help applying for financial assistance and prescription drug programs, hotel discounts and money for meals (for those traveling for care), and grocery and rent assistance. A local support organization also provided housekeeping assistance. One survivor mentioned an organization that assisted with prosthesis. However, not all participants were aware of such support services, and others indicated that they were aware of the local foundation but did not qualify for services because they lived too far away.

In addition to organization-based support, participants described social support which played an important role in their cancer journey. Staff (eg, nurses, navigators, social workers, and therapists) were described as “nothing short of wonderful” and “like family.” The survivor who was also a caregiver noted that the staff “celebrated all of the holidays with us.” Family and friends also played a key role for most participants. Family and friends were a primary source of informational, emotional, and instrumental support. As 1 survivor noted, “The biggest support I got was from church, family and friends.” A survivor from an outlying community noted, “One of the big advantages to living in a small town is that your community is kind of your support.” He provided examples of how his community came together to help him with yard work and wore t-shirts supporting him. Another participant from an outlying community utilized the hour drive time to and from treatment to call friends and contacts. However, not all participants had robust social support. The participant with dual roles described delaying her own cancer treatment while caring for her husband as he died from cancer. Another survivor related, “My wife told me with her anxieties, she couldn’t handle [my cancer diagnosis] so I was on my own

and it was kind of rough.” Cancer support groups, such as A Time To Heal (<https://atimetohealfoundation.org/>), also provide informational and emotional support. “We get questions answered and we are armed with information that we ask our doctors, so that is what I would recommend.”

DISCUSSION

Once rural patients have received a diagnosis and are referred to local cancer centers for specialized care, they have access to supportive services, such as care navigation, social work, and financial and travel assistance. However, such assistance may be geographically limited, thus emphasizing the barriers faced by those living far from the treatment center. Care coordination at the initial stages of symptom identification and diagnosis varies greatly by doctor, highlighting rural provider- and system-level barriers that can lead to delays and undue patient distress associated with a new cancer diagnosis.

Cancer diagnosis experience

Approximately half our participants were diagnosed based on self-identification of symptoms or through “unrelated” care for conditions, including sepsis, pneumonia, and osteoporosis. The latter group of patients took weeks to more than 1 year before they received a cancer diagnosis. Screening accounted for the other half of diagnoses. It should be noted that neither lung cancer case was identified from screening, which is recommended annually for current and former (quit within past 15 years) smokers aged 50-80 with a 20 pack-year smoking history.³⁷ In 2016, only about 1.9% of eligible smokers were screened for lung cancer.³⁸ A study conducted in rural New England found a lack of knowledge about lung cancer screening and not receiving information or recommendation from health care providers as 2 primary reasons for screening underutilization despite participants being open to receiving lung cancer screening.³⁹ Because the smoking rate is higher in rural than urban communities,⁴⁰ rural residents, as well as providers, may need additional education about lung cancer symptoms and screening recommendations.

Patient-level barriers

Our participants identified several barriers that can be generally classified according to the categories established by the American College of Surgeons Commission on Cancer: patient-, provider-, and health system-based barriers.^{41,42} Our findings are congruent with previous studies that identified patient-level barriers among rural residents, including finances (treatment cost and insurance coverage), transportation, and lack of social support.⁴³ Finances are a well-known barrier to cancer care. Financial toxicity diminishes quality of life and can impede optimal care.⁴⁴⁻⁴⁷ A study that examined the Health Information and National Trends Survey (2012, 2014, and 2017) indicated that

half of rural cancer survivors experienced financial problems due to cancer compared to 38.8% of urban survivors.⁴⁸

Some participants were able to identify resources to address patient-level barriers, such as financial assistance and cancer support groups, but not everyone was aware of or able to access such supports, particularly those from outlying communities. Social support can take many different forms, including informational, emotional, and instrumental support.⁴⁹ Our study reinforced the importance of informal caregivers (family and friends) in the cancer journey. Koenig Kellas and colleagues reported that survivors, caregivers, and oncology providers viewed cancer as an experience that brings family and cancer care team together in a “shared, communal, relational, experience of cancer care.”⁵⁰ At the same time, many caregivers indicated barriers to taking a communal approach in cancer care—lack of information, isolation, avoidance of cancer-related topics, and lack of understanding of different points of view experienced among survivors, caregivers, and care team members. Culturally, rural communities value community and family approaches to addressing health problems. The concept of communal experience in cancer care may be an important topic for future research.

Provider- and system-level barriers

Provider-level barriers were clinician attitudes, perceptions, and communication, and physician turn-over. System-level barriers included fragmentation of the medical system (as evidenced by referral for diagnostic testing and transfer to specialists) and lost or delayed results.³² Only about 28.5% of Nebraska’s primary care needs are currently met,⁵¹ with health professional shortage areas located across the state.⁵² Hiring and retention of both primary care and specialty cancer care thus impact services from screening to treatment and follow-up in rural areas. Additionally, the sparsity of specialized providers meant that patients had limited options if a doctor lacks rapport. Care coordination and patient-provider communication were 2 of the major concerns expressed by our participants. Two studies conducted in rural Australia identified similar barriers to cancer care found in our study: confusion about the roles and responsibilities of the different members of the health care team, lack of comprehensive multidisciplinary team meetings, a problem with transitioning care due to lack of communication and effective referrals, inadequate communication between specialist and primary care, inadequate access to health services especially in rural communities, and undersupply of cancer specialists.^{53,54}

A US study found that availability of a family caregiver was significantly positively correlated with perception of better quality of communication among care team members and between patient and provider.⁵⁵ Also, further emphasizing the aforementioned need for social support, the presence of a family caregiver was significantly positively associated with better perception of information about financial resources and emotional support.⁵⁵ Recognizing the complexity of cancer care, some institutions hire an individual to coordinate care, such as a nurse or lay navigator. A systematic review reported that cancer care coordination interventions are effective in 81% of outcomes

being examined, including cancer screening, measures of patient experience with care, and quality of end-of-life care. Patient navigation was the most frequent care coordination followed by home telehealth and nurse case management.⁵⁶ Moser and Narayan also advocate the use of digital tools to increase the effectiveness of communication among cancer care team members.⁵⁷ Specifically, they discussed the potential usefulness of artificial intelligence (AI) in assisting with planning, facilitation of tasks, care transition, and symptom management and education about health promotion. AI-assisted digital tools can be used by rural care team members, including navigators and patients to promote coordinated and data-driven cancer care.

Diversity of rural cancer patients

Participants from our largest focus group were aware of the racial/ethnic and cultural diversity within their community and the unmet needs related to cancer care and medical care in general. A review study discussed the need to focus increased efforts to understand and address cancer disparities experienced by racial/ethnic minority populations living in rural communities.⁵⁸ More research is needed to address the intersection of rurality and minority status as well as research that examines how best to deliver evidence-based practices to reduce health disparities in these populations.

Strengths and limitations

We had a relatively small number of rural individuals who self-selected to participate, which may bias results. Partly due to smaller focus group sizes, we were able to have in-depth discussions about cancer journey experiences. Including caregivers and survivors in the same groups offered varying viewpoints and enriched discussion. Many participants thanked us for the opportunity to share their stories. Our focus groups were held virtually due to the COVID pandemic. We screened for technology access at recruitment, and all had the ability to participate. Only a few people requested Zoom training, so we believe technology barriers were minimal. Virtual groups also meant that participants could participate from the privacy of their own homes without needing to travel, thus potentially allowing more people from outlying areas to participate. Virtual groups were also time and cost efficient. Because the study was conducted in a Midwestern state, findings may not be generalizable to other rural communities.

CONCLUSIONS

The cancer burden in rural populations differs from the general population in terms of incidence, diagnostic stage, mortality, and survival, as well as health care access. Thus, their cancer perspectives and experiences are unique. Focus groups and need assessments are important to identify barriers, gaps, and additional resources needed to decrease cancer health disparities in rural populations. Results from our study

are being used by the statewide cancer coalition, state comprehensive cancer control program, and the only National Cancer Institute-designated cancer center in the state to prioritize outreach and interventions aimed to reduce rural disparities. These organizations, as well as their clinical and community partner organizations, are identifying specific action steps. Examples of such efforts include: (1) partnering with community organizations and rural cancer centers to revitalize lay cancer navigator programs; (2) conducting webinars for primary care and cancer specialty providers in rural communities to discuss these findings and identify potential interventions; and (3) collaborating with national and regional cancer support organizations to expand reach in rural communities.

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DISCLOSURES

The authors have nothing else to disclose.

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