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Perspectives of cancer prevention and control resources from stakeholders in rural southern Illinois

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Abstract

Purpose: Rural residents have a higher cancer burden than urban residents, which is likely related to multiple socioecological factors. This study sought to investigate the perspectives of a diverse set of rural stakeholders regarding access to cancer prevention and control resources in rural southern Illinois.

Methods: Stakeholders were recruited from counties in southern Illinois and included residents (cancer survivors or caregivers), leaders of community-based organizations with health-related missions, and health care providers. Individual interviews and focus groups assessed recommended cancer prevention, control, and treatment resources; helpfulness of regional resources; and needed resources. The research team used an iterative approach to thematic analysis wherein codes were derived inductively and refined repeatedly to reveal overarching themes.

Findings: Forty-four stakeholders reported challenges to health care access (eg, travel distance, financial burdens, and poor quality of care) and limited access to supportive care services (lack of caregiver support and “spotty” area resources). To mitigate these barriers, local residents used a combination of individual (self-reliance and adaptive measures) and organizational (patient navigation and financial services) approaches. Finally, stakeholders reported multiple forms of cancer control and prevention communication, including formal discussions with health care providers and various types of informal social support (eg, friends and family).

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Conclusions: Stakeholders experienced barriers to cancer prevention and control often mitigated by a reliance on personal adaptations, nonclinical organizational supports, and informal support systems. While resources remain minimal in southern Illinois, researchers and practitioners must make efforts to leverage existing community organizations and social networks to improve cancer outcomes in this region.

Keywords

cancer control; cancer prevention; Illinois; qualitative research; rural health

The American Cancer Society[1] estimates approximately 1.8 million cancer diagnoses in 2020, a 2.5% increase from 2019.[2] This cancer burden is unequally distributed, with individuals living in rural counties experiencing 2.7% and nearly 10.0% higher incidence and mortality rates, respectively, than their urban counterparts.[3] In particular, incidence and mortality for preventable cancers[3]—such as breast, prostate, colorectal, kidney, and lung cancer—are disproportionately higher in rural areas.[3–5] Further investigation is necessary to identify socioenvironmental and socioecological factors that impact rural community members' perspectives of cancer control. Disproportionate cancer outcomes in rural areas are likely related to multiple socioecological factors. Individual behaviors associated with multiple cancers, such as tobacco use and sedentary behavior, are more prevalent in rural areas.[4, 6, 7] However, individual factors do not fully explain poorer rural cancer outcomes. Individuals in rural areas are likelier to have limited access to care, often due to transportation and financial concerns,[6, 8] and fewer choices for care, often necessitating lengthy travel to visit health care providers.[6] Concerns related to accessibility are often compounded by individuals needing to take time off work (ie, lost wages), find childcare, stay overnight, and pay for transportation costs.

One heavily rural cancer hotspot is the Mississippi Delta Region (MDR), an area comprising counties within Alabama, Arkansas, Illinois, Kentucky, Louisiana, Mississippi, Missouri, and Tennessee with high unemployment, inadequate health care access, and low levels of health literacy and education.[9–12] This region is also part of the Delta Regional Authority, a federal-state partnership dedicated to improving living conditions throughout the 8-state region, including increasing access to quality health care services.[13] The region's northernmost counties reach into southern Illinois, making it a distinctive region within both the MDR and Illinois. All 16 Illinois MDR counties are designated Health Professional Shortage Areas (HPSAs), and 15 are Medically Underserved Areas,[14–16] access issues that contribute to worse cancer outcomes, including late-stage diagnosis or delayed medical care.[17–19] Compared to central and northern Illinois, southern Illinois counties have lower median income, increased poverty, more uninsured individuals, and fewer people over age 25 who graduated high school.[8] Moreover, southern Illinois has a higher age-adjusted annual cancer incidence rate (480.6 per 100,000 individuals) than the state (465.5) and US (448.7).[20]

Narrower in scope, the 7 southernmost counties of Illinois—the Southern 7 (S7)—experience higher socioeconomic burdens than any other counties in southern Illinois. The S7 includes some of the most remote rural counties in Illinois, 2 of which are the least populated in the state. The 2019 estimated population for the S7 is approximately 63,500 residents across 1,975 square miles,[21] over 18% of whom live in poverty. The median household income is $43,685, approximately $20,000 less than the state average.[22, 23] Along with the lack of regional medical resources, these socioeconomic factors contribute to the region's higher age-adjusted cancer mortality rate (199.6 per 100,000 population) as compared with US (155.5) and state rates (161.7).[24] The S7 is also sociodemographically unique, with diversity not found in central and southern Illinois (eg, Alexander and Pulaski Counties are 31.8% and 30.6% Black, respectively, whereas Illinois is 14.6% Black).[25] Due to the S7's shared cancer burden with the MDR, importance in southern Illinois as a racially and ethnically distinctive area, and reduced access to health care facilities, this region is an exemplar for exploring socioecological factors that impact access to cancer resources. As such, we sought to investigate regional stakeholders' perspectives about access to cancer prevention and control resources in the S7.

METHODS

Stakeholders and setting

The S7 mostly comprises counties classified as nonmetro, codes 4–9, according to the Rural Urban Continuum Codes (RUCC).[26] One county, Alexander, is classified as RUCC 3 but shares similar characteristics with neighboring counties. This region is characterized by its shared health department,[27] geographies and economy, and designation within the Alvin J. Siteman Cancer Center Catchment area.[14] We used community-based participatory research (CBPR) practices to build community-academic partnerships and engage community members throughout the research process, including developing research questions and study design, formulating a recruitment strategy, and disseminating findings.[28, 29]

Recruitment

We purposively recruited stakeholders, a term referring collectively to all study participants, comprising community-based organization leaders and health care providers. All S7 residents (herein "residents") were cancer survivors or caregivers currently residing in the S7. Community-based organization leaders (herein "leaders") were self-identified leaders of organizations that served as an S7 health information repository (eg, churches, libraries, and civic organizations). Health care providers (herein "providers") practiced in a clinic in the S7. All stakeholders were English-speaking and at least 18 years old.

Most were initially identified and approached by a central community partner who is a life-long resident of, and community health advocate within, the S7. Others were recruited via snowball sampling,[30] wherein an enrolled stakeholder referred other potential stakeholders. No passive recruiting strategies (eg, flyers and brochures) were used. All participating Institutional Review Boards approved plans for recruitment and data collection.

Data collection

Interviews and focus groups were conducted from May 2018 to August 2019. First, we conducted semistructured interviews with leaders and providers individually to accommodate their schedules. We partnered with leaders as a CBPR recruitment strategy to increase referrals for potential resident interviews. Residents were primarily interviewed via focus group, though we permitted individual resident interviews when (1) requested due to barriers to focus group attendance (eg, recurrent rescheduling, transportation barriers, and physical limitations) or (2) suggested by a study investigator due to inability to recruit enough participants from the same county to conduct a focus group. By allowing individual resident interviews, we were able to capture perspectives from residents of as many counties as possible.

Investigator-developed interview guides did not differ for focus groups and interviews, though guides were tailored for residents, providers, and leaders. Guides, which were reviewed and piloted with a qualitative research expert with a history of leading NIH-funded qualitative studies in rural settings, an S7 leader, and an additional resident, assessed stakeholders' views on (1) recommended and available cancer prevention, control, and treatment resources; (2) helpful existing resources for cancer patients and caregivers; (3) less helpful existing resources and services; and (4) needed additional resources to address cancer prevention and control. Residents were asked to consider resources both within and outside of the S7.

All interviews and focus groups were conducted either over the phone or at trusted county-specific community locations selected by stakeholders (ie, personal homes, libraries, and school classrooms). Two experienced researchers (ML-T and AK-D) trained in CBPR and qualitative methods moderated all interviews and focus groups. Sessions began with a 1-page demographic survey and were audio-recorded with digital recorders and supplemented with field notes. Individual interviews were approximately 45 min, and focus groups were approximately 90 min. Each focus group included 3–7 residents from the same county. All project stakeholders received a $20 gift card incentive.

Analysis

Audio-recordings were transcribed verbatim by a professional transcription service. To ensure transcription accuracy, an investigator (ML-T) compared random samples of audio to the transcript text, and inaccurate text was retranscribed by the transcription service. Transcripts were thematically analyzed both deductively (ie, aligned with research questions) and inductively (ie, "bottom-up") to uncover patterns.[31] Each transcript was individually coded, and results were compared to ensure reliability. Investigators (AK-D and ML-T) met regularly to discuss emergent codes and develop a codebook, and in the rare situations when investigators disagreed on codes, a third investigator (ie, the qualitative expert mentioned previously) was brought in to mediate and resolve discrepancies. During the second read of the transcripts, emergent codes were derived from the raw text and added to the codebook. Data collection continued until both investigators agreed saturation was reached. Thematic saturation is the iterative review process of collected data to assess that no new information or themes emerge.[32, 33] NVivo 12 (QSR International, Melbourne, Australia) was used to manage data, and the consolidated criteria for reporting qualitative research (COREQ) was followed in reporting findings.[34] Trustworthiness of the study was established via multiple methods, including source triangulation (eg, interviewing stakeholders with differing perspectives), debriefing with academic peers well-versed in qualitative research, stakeholder member checking, using thick description to promote transferability, and including multiple investigators with unique backgrounds to encourage self-reflection and reflexivity.[35, 36]

RESULTS

Description of sample

Most stakeholders were 45–74 years old, female, with at least some college education. Non-Hispanic Black and White stakeholders were about equally represented. Only leaders and residents were asked about insurance status, 90% of whom had insurance (49% Medicare or Medicaid). Only community residents reported income, and about half had an annual household income of ≥$50,000. Thirty-one residents participated, 9 of whom were interviewed individually via telephone and the rest via focus groups (Table 1). Stakeholders reported on 3 major themes regarding cancer resources in the S7: (1) regional services and needs, (2) strategies to access resources, and (3) communication regarding access to regional resources.

Regional services and needs

Stakeholders’ descriptions of regional needs were mainly systemic in nature, including concerns regarding local health care quality and a general lack of available regional options, particularly related to cancer treatment. Additionally, they described multiple social determinants that influenced access to appropriate care. Table 2 provides exemplar quotes not presented in the description of subthemes below.

Lack of proximal services—The most commonly discussed barrier to accessing care related to a lack of regional services that necessitated travel—particularly for specialty treatments like oncology, but also for basic services (eg, lab work and screenings). Multiple stakeholders identified St. Louis (~120 miles away) as the closest specialty care location, mainly because it had locations that accepted various insurance providers, but others traveled as far as Chicago or Nashville to see an oncologist. Stakeholders noted that, for many S7 residents, this travel required an overnight stay. One resident commented:

> It’s just frustrating that you have to travel as far as… an hour, or plus, to receive a chemo treatment. Or an infusion. Or, you know, a radiation? And then, you know, you’re sick already from the treatments. Then, you know, you have 1+ hours on the road to get back home.

Travel distance became even more problematic when compounded by lack of reliable or consistent transportation. Given that many patients relied on family for transportation, it could “[put] some stress on their family in trying to be able just to get the person to where they’re going… if it includes an overnight stay.” These issues often led to residents not following through with appointments. Nevertheless, stakeholders acknowledged individuals had other transportation options, the most commonly cited being a low-cost regional mass transit bus serving the 7-county district that could be booked by telephone with 2-h notice.

Perceptions on the quality of regional services—Multiple perspectives on regional service quality emerged, with some stakeholders remarking that recently built nearby specialty care centers improved regional health care quality. A provider pointed out that the recently opened “breast center…has been excellent as far as getting our patients in without it being a big deal or hassle,” and a resident commented positively on a local hospital that had been “broadening [its] services.” Despite an overall lack of facilities in the S7 itself, stakeholders expressed happiness with service quality from area cancer-specific auxiliary services, such as the American Cancer Society, local fundraisers and events, church programs, and a regional university’s exercise program for cancer survivors.

Conversely, others perceived the lack of regional health care services as emblematic of poor care quality, especially since the paucity of services often necessitated long wait times to see providers. One resident noted, “If you have… an immediate issue, you’re not getting in anywhere anytime soon.” Furthermore, stakeholders connected poor service quality to worse cancer outcomes, as shared by 1 resident:

> This person had a spot on the skin. They went to…one, two, three doctors [who] couldn’t tell him what was going on. They go to [a St. Louis cancer center] and he’s there for five minutes and the doctor says, “Oh I know what you got. This is what it is.” Now two years went by without diagnosis and it was too late. It got him.

Some negative perceptions of regional service quality were related to the close-knit nature of many rural communities, whereas others were explained by materials and technology at local facilities that were old or out of date. One resident stated, “It’s a small town, so everybody knows everybody,” raising concerns that private health information would “get out” or be shared inappropriately. Regarding outdated technology, a resident noted, “[It would help] if they were able to get some machinery… Of course, they got the X-ray machine out there, but it’s lackin’. They’ve got the mammogram machine out there, but… those are old ones.”

Systemic factors influencing access to regional services—Stakeholders listed a number of systemic factors that promoted or impeded ability to access regional services. Some difficulties in access stemmed from the region’s rurality, with 1 leader noting:

> We’ve accepted that we live in a rural environment, and that’s gonna be a barrier. It’s a barrier for anything. It’s not just cancer… Just getting someone to where they need to go to get that treatment, that in and of itself is an issue.

Stakeholders also believed the limited number of regional resources impeded cancer prevention. One provider commented, “if we’re thinking about healthy lifestyles and diet… we are a nutrition desert in Cairo [IL]. We have no grocery store. We have three liquor stores, but we have no groceries.”

Insurance concerns were cited by stakeholders as an issue affecting access. One leader stated, “Most of the people here either have Medicaid or no insurance, so there’s no prevention. By the time they go to the doctor, they’re very sick.” Common insurance concerns left patients with limited options for specialty care, with “[s]ome patients…

[having] to switch from one plan to the other just to get a referral because with only Medicaid, a lot of specialist doctors…don't even take it." In other cases, providers singled out Medicaid recipients: "There is a difference in treatment with a medical card as opposed to medical insurance. You're received differently, you're handled differently."

Lastly, stakeholders discussed difficulties in meeting various qualifications to participate in programs to help people prevent or manage cancer, such as the requirement for documentation. One resident commented, "It's just they want everything. I need 20 check stubs… You need all of these documents and you're thinkin', really? I'm going through chemo. I don't care about that right now." Others believed that assistance programs had prohibitively low-income cutoffs, leaving many patients ineligible to receive assistance.

Strategies to access resources

Regional difficulties in accessing health care resulted in increased reliance on individual-level and systems-level strategies and resources to fill gaps, including individual adaptive measures and reliance on local organizations and faith communities for support (Table 3).

Individual adaptive measures—Adaptive measures describe coping strategies used by individuals to either acquire, substitute, or reconcile the lack of critical cancer resources. Stakeholders remarked that the lack of regional resources required self-reliance to manage health. As a resident stated, "You've got to be involved with your own health, and you can't let a doctor take… that job. Your job is to know your body and to help with the decision making." Another commented, "I think that the information is there, but we're really lax with going after the knowledge that's there for us."

Others discussed a need to make personal or lifestyle adaptations. One resident mentioned they had to quit their job in order to take care of a family member with cancer. Another mentioned they were forced to decide between working and caregiving, ultimately choosing work because they needed money to care for their loved one.

Formal and informal organizational-level strategies—Stakeholders identified grassroots and formal support systems to assist with cancer prevention and care, many referencing faith-based organizations: "Local religious groups…offer rides for anyone who needs them." Another resident discussed how churches help financially, commenting, "The local churches… help financially a lot of times with families…when they've got long-term issues, trying to get to and from treatments and things like that."

Others described assistance from governmental and community-based organizations. A leader described how their community had a memorial fund that "was able to give out almost $300,000.00 to cancer patients in [the county]." Another identified the local health department as having "grant monies for individuals that have no health insurance or health insurance that doesn't cover the appropriate testing for breast cancer or any type of cervical cancer." Finally, stakeholders discussed formal resources, such as patient navigation and coordinated care, which were available to help them manage their cancer care:

> If you wanted to use [the nurse navigator], you would just call her on the phone, and she, specifically, would find you while you were in treatment and start from there and see…how you were progressing.

Other organizational resources identified by stakeholders included facilities, such as hospitals, hospice, and social services; service-based organizations, including those affiliated with hospital systems, insurance programs, and universities; and national and state organizations.

Communication regarding access to regional resources

Stakeholders identified multiple channels used to gather and relay information, the 2 most dominant being (1) through health professionals, and (2) among peers (Table 4).

Communication with health care professionals—Health care providers stated they encouraged patients to manage their own care, 1 of whom commented:

> Nobody cares about you more than yourself. Make sure that you know what's going on. Make sure you have a copy of those records and know what the plan of action is…Your oncologist's gonna help with this plan, but you also need to know what's going on and be an advocate for yourself.

Despite providers' advocacy for self-management, distrust in providers or medical systems impeded effective patient-provider communication. A resident acknowledged that distrust prompted people to "avoid goin' to the doctors" and that, "by the time they go to the doctor, it's too late." Another barrier to patient-provider communication was residents' perception that cancer was inevitable: "I always make a joke that I don't go to the doctor 'cause… if I go to the doctor with a headache, I come out with cancer of the toe."

Health communication for patients and caregivers was also of concern. One leader stated, "No efforts [are] made to make sure that the patient is connected with appropriate services, that they have followed up, that they have kept their appointments." Specifically, caregivers expressed a desire for stronger communication from health care providers and sometimes felt underqualified to care for loved ones, especially when clinical services closed, adding to caregiver responsibilities.

Health communication with other community members—Peer communication—"word of mouth" conversations between peers, family members, and others around the community—was frequently used to identify resources and navigate the health care system. One leader commented, "We don't have a lot of resources, [so] we…depend on [what] people [have] to say." Peer communication was used to recommend physicians, hospitals and associated services, financial resources, and insurance information. A resident described, "Through [a] ladies' group in our church, we like to go in from time to time and…talk and see what's going on about health care and about screenings and who goes where." Notably, written and digital health information was not a common modality of health communication, as described by another leader: "I mean, they may put it out there, [but] we just may not read it… Word of mouth is the biggest thing."

Peer communication also provided emotional support which, periodically, substituted for minimal regional psychosocial support services. A resident commented, “If I had to talk about a support system, my—our—support system was each other. We were all we had.” Responding to the lack of formal caregiver support groups, a resident replied, “I’ve been a caregiver as well, and there’s just not a lot…that I’m aware of. I have a large family, so we all kind of figure it out, you know.” Much emotional support was provided through informal connections between family members, friends, church families, and other organizations. Stakeholders strongly endorsed support groups as a needed resource.

Nevertheless, some discussion emerged regarding support groups and privacy. Privacy concerns were especially noticeable in focus groups with a larger representation of men. In 1 group, a male resident revealed that “most men are not comfortable” talking about health concerns in a group setting like a support group. Another leader described cancer as “a bad word,” with associated fears hindering cancer communication among peers.

DISCUSSION

This study adds to the growing literature highlighting challenges associated with rurality and cancer care. Stakeholders revealed multiple regional cancer prevention and control needs that must be considered in the context of minimal available services, concerns about service quality, and other systemic barriers that reduce access to care. Some of these findings—such as transportation concerns[37–39] and the use of nurse/patient navigators,[40, 41] for example—have been emphasized in previous research on rural cancer care. However, others are more novel findings, such as the emphasis on informal health communication as a strategy to understand care needs and access resources, stakeholder concerns about outdated health care machinery, and issues with program qualifications to receive services. Cumulatively, our findings punctuate the role of interpersonal ties in rural health and emphasize the importance of continued research to explore pathways by which rural social networks impact cancer prevention and control.

Stakeholders discussed the role of social connectedness in identifying reliable health care resources, overcoming critical care gaps, and providing useful health communication. With limited formalized cancer-focused social groups and resources, stakeholders relied on strong interpersonal connections, a phenomenon supported in the literature as a method used to mitigate gaps in rural health care.[42] In rural communities, trusted health education and communication hubs often include family and friends, places of worship, community colleges, community organizations, and barbershops.[43, 44] Stakeholders in our study relied on “word of mouth” to recommend services, provide advice, and share health communication among themselves; however, it is important to note that social networks tend to represent the values of the networks’ members and are thus often self-selecting and highly exclusive.[45] As such, the relatedness between social connections and rural health might also facilitate inconsistent dissemination of health information, rendering certain social networks with more or less accurate health information and access to resources.[46] To this end, investigations and programs developed for rural communities must consider diverse pathways to engage stakeholders and disseminate health information.

Access to cancer control and prevention resources required a high level of self-management among stakeholders. Self-management was often informed by social networks or health care professionals and supported by accessible and trusted health care resources. Furthermore, stakeholders implied that self-management extended to personal responsibility to manage or comanage one's family's health. Whereas other studies have reported rural patients used tools, such as eHealth or mHealth technologies, to access resources or manage care,[47–51] in our study, few commented on the usefulness of technology. Also, while the role of social networks was emphasized for self-management, few other studies on rural cancer care have reported similar findings. For example, Adams and colleagues[52] found that rural African American breast cancer survivors preferred *not* to talk about their disease management with family and friends. One possible explanation for our divergent findings is that many stakeholders noted a general lack of reliable and trusted area health education resources, a finding supported by studies that have identified health literacy limitations and needs for rural cancer patients.[53]

Lastly, stakeholders identified gaps and barriers related to accessing community- and practice-based resources. Community organizations and health care facilities often share the responsibility of improving health outcomes, and contextual attributes—the designation as a health shortage resource area, poverty index, and built environment—each influence the health status of rural communities.[54] In southern Illinois, cancer control and prevention resources were limited, but stakeholders identified incremental advancements that improved and expanded existing resources; for example, stakeholders welcomed the recent building of a local cancer center. Nevertheless, most discussions focused on spotty or nonexistent community resources, leading to longer wait times, wait-listing, or travel to access resources. These lengthy wait times were often interpreted as an indicator of poor quality and questionable trustworthiness, and residents thus often preferred to use services in distal urban centers. This perspective may, in part, explain the urban-rural paradox of inconsistent differential effects seen in travel distance and health outcomes between urban and rural patients; specifically, studies have found that increasing distances to health care facilities are positively associated with receiving care for rural patients, but not for urban patients.[55–57] In an investigation of the receipt of primary surgical management for cervical cancer patients, urban patients living ≥15 miles from a surgical facility were less likely, but rural community members living ≥15 miles from a surgical facility were almost twice as likely, to receive treatment.[56] For these reasons, it is important that larger urban cancer centers develop and maintain partnerships with regional health care clinics so residents can receive basic services within their own communities and be linked to follow-up care at cancer centers, if necessary. Using CBPR approaches can help researchers uncover needed improvements to regional care to promote greater community trust and use in these services.

LIMITATIONS

This study is strengthened by the inclusion of a racially and socioeconomically diverse sample of rural southern Illinois stakeholders, but it is not without limitations. We conducted an exploratory study of rural stakeholders from 7 counties, and caution should be taken in generalizing these findings to larger rural regions. Our recruitment strategy oversampled for S7 community residents—70% of the sample. Notably, to overcome potential recruitment barriers of recruiting providers and leaders in a region considered an HPSA with limited community organizations, residence in the S7 did not determine eligibility for providers and leaders. Therefore, although our inclusion of multi-level perspectives and a large representation from residents of the S7 are study strengths, the perspectives of leaders and providers were limited and reflect their limited availability in the S7 region. Future research should attempt to oversample regional health care providers, though due to the aforementioned issues, this task may be challenging. We also relied on a small number of leaders to refer residents, potentially introducing sampling bias by oversampling residents already highly engaged in their community and the health care system, though snowball sampling was used to mitigate potential sampling bias and increase our likelihood of reaching diverse stakeholders. Although focus groups and interviews were facilitated by experienced researchers using rigorous research protocols and procedures, it is possible that data interpretation may contain participant and researcher bias. Similarly, codes used to develop themes and, ultimately, the study findings are limited by the researchers' judgment and restricted to concepts and interpretations of meaning deemed appropriate by the consensus of the interviewing researchers (AK-D and ML-T).

CONCLUSION

For rural stakeholders of southern Illinois, accessing cancer prevention and control resources is largely shaped by regional services and needs. Trust in service quality and recommendations from community members and health providers are determinants of access. For rural community members, accessing quality health care resources is complicated by transportation, financial, or health information barriers. Future research should test tools to organize identified resources to be used in an intervention targeting improved cancer care for these community members. There is great promise in leveraging social connectedness in the S7 to build productive academic-practice-community relationships that advance health promotion research and improve rural cancer outcomes.

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Table 1.

Stakeholder characteristics

	n	%
Stakeholder[a]		
Healthcare providers	4	10
Community leaders	9	20
Community residents	31	70
Age		
25–44	7	16
45–64	22	50
65–74	12	27
≥75	2	4
Sex		
F	32	73
M	11	25
Race/Ethnicity		
Non-Hispanic White	22	50
Non-Hispanic Black	19	43
Hispanic White	1	2
Other	1	2
Education		
≤ HS diploma/GED equivalent	3	7
Some college	13	30
Associate’s	8	18
Bachelor’s	5	11
Master’s	12	30
Doctoral	2	5
Insurance status[b]		
Yes	37	93
Insurance type		
Medicare/Medicaid	18	49
No	1	3
Annual household income[c]		
<50,000	12	37
≥50,000	15	48
Decline	2	6

[a] Nine stakeholders completed individual telephone interviews, 32 stakeholders participated in in-person 4 focus groups.

[b] Only reported by community leaders and residents.

[c] Only reported by community residents.

Note: Data missingness is 3% for all categories except income, which is 6%. N = 44.

Table 2.

Subthemes and exemplar quotes corresponding to the regional services and needs theme

Subtheme: lack of proximal services	
Speaker	**Quote**
Leader	I think most helpful would be bringing the screening options closer to them, in their own communities, so they don’t have to reach out and do some of those. I know some of them you can do kits and mail it off.
Leader	I think people need—know that they need to go get screened, but if it’s not close by, obviously, I think there—that’s their—the correlation with the high numbers in our area is because people aren’t accessing it. Even though there may be free screenings out there. It may be that’s an easy thing to go do, and maybe it’s not expensive, but just because it’s not nearby, I think that a lot of people aren’t getting screened.
Leader	I know it’s very difficult to get in, and sometimes it incorporates an overnight stay because of how long they’re receiving treatment and then having to come back the next day.
Leader	She has to ride that bus for five hours after a treatment. She’s stuck on this bus, going, stopping, going, dropping all these other people off.
Resident	Most people traveled to St. Louis, which is a two-and-a-half—two—two-and-a-half or three hours, depending where in St. Louis.
Resident	And I shouldn’t have to go 40 minutes to the doctor.
Subtheme: perceptions on the quality of regional services	
Leader	I try to get them to go to St. Louis—a larger area—because of the conditions here. We’ve lost a couple people to cancer through bad treatment.
Resident	I’m constantly asked what my needs are, and that’s—I feel really strongly about that and, also, the fact that, um, I am taken, you know, as a priority, and that makes a big difference.
Resident	When I was goin’ down to Cairo, it took a little while for them to get around to gettin’ me to somewhere to get worked on. So like they maybe they need a little faster movement.
Resident	He had went to all these doctors around in southern Illinois, and none of ‘em told him he had cancer.
Resident	There’s this perception that if you stay local that it’s not a good choice. So there’s—there’s a stigma out there that you can’t get good treatment locally.
Resident	The people with the best resources are getting the best treatment, and that’s not how- that’s not how you equalize things. that’s not how you get things better.
Subtheme: systemic factors influencing access to regional services	
Provider	If we’re thinking about healthy lifestyles and diet, one thing—we are a nutrition desert in Cairo. We have no grocery store. We have three liquor stores, but we have [laughter] no groceries.
Provider	Some patients actually had to switch from one plan to the other just in order to get a referral because with only Medicaid a lot of specialist doctors, they don’t even take it.
Resident	You know, when you go out to—when they go out to door, you can’t go nowhere but the Dollar Store and to post office and-and to the bank. You can’t go nowhere. There’s nowhere to go, you know. Now we don’t have no gas station. We don’t have no drugstores, don’t have the grocery stores.

Table 3.

Subthemes and exemplar quotes corresponding to the strategies to access resources theme

Subtheme: individual adaptive measures	
Speaker	**Quote**
Leader	We have to try to change people’s mindset too. A lot of times our community, we just don’t wanna go to the doctor.
Provider	A lot of our patients wait, or they don’t seek care until that disease or chronic condition is well based.
Resident	You’ve got to be involved with your own health, and you can’t let a doctor take, you know, t- take that job. Your job is to know your body and to - to help with the decision making.
Resident	You gotta make up your mind whether you gonna live through it or whether you’re gonna die trying.
Resident	I think that the information is there, but we’re really lax with- with going after the knowledge that’s there for us.
Subtheme: formal and informal organizational-level strategies	
Leader	Has grant monies for individuals that have no health insurance or health insurance that doesn’t cover the appropriate testing for breast cancer or any type of cervical cancer
Resident	And, you know, local religious groups that would offer rides for anyone who needs them. But nothing really organized and structured.
Resident	The local churches because, many times, there’s been a lot of families that are not able to, um—well, they help financially a lot of times with families who are not able, uh, to get to and from—when they’ve got, um, long-term issues, trying to get to and from treatments and things like that.
Resident	In our history of the memorial, we’ve been able to, since 1997 when we officially got started, but since ’95, actually, we’ve been able to give out almost $300,000.00 to cancer patients in Johnson County.
Resident	They pretty much assigned you one. And if you wanted to use it, you would just call her on the phone, and she - and she, specifically, would find you while you were in treatment and start from there and see, you know, what you were doing and how you were progressing.

Table 4.

Subthemes and exemplar quotes corresponding to the regarding access to regional resources theme

Subtheme: health communication with health care professionals	
Speaker	**Quote**
Leader	No effort's made to make sure that the patient is connected with appropriate services, that they have followed up, that they have kept their appointments. Is there a transportation issue? What's going on?
Leader	Show them how to do the colostomy bag
Provider	Nobody cares about you more than yourself. Make sure that you know what's going on. Make sure you have a copy of those records and know what the plan of action is. Because what it all comes down to is you love yourself more than anybody else on this earth. Your oncologist's gonna help with this plan, but you also need to know what's going on and be a advocate for yourself.
Resident	Avoid goin' to the doctors.
Resident	Unfortunately, by the time they go to the doctor, it's too late.
Resident	Interviewee: But, uh, a lot of this is mostly communication and people just don't—they seem like they don't care anymore. You know, just—you tell 'em 'bout cancer and— Interviewee: A lack of hope? Interviewee: Yeah.
Resident	I always make a joke that I don't go to the doctor cuz, whenever I go to the doctor—if I go to the doctor with a headache, I come out with cancer of the toe.
Resident	I had to give shots in my husband's stomach, and his little tummy got so—where it looked so bad, and I just needed somebody to say, "that's okay. that's—that's gonna—that's gonna look like that."
Subtitle: health communication with other residents	
Leader	We don't have a lot of resources, we do depend on people to say.
Leader	I mean they may put it out there we just may not read it. Word of mouth is the biggest thing.
Leader	Cancer is a bad word.
Resident	Through another ladies group in our church, we like to go in from time to time and sit and, you know, talk and see what's going on about healthcare and about screenings and who goes where.
Resident	So, if I had to talk about a support system, my—our support system was each other. We were all we had.
Resident	I've been a caregiver, as well, and there's just not a lot, uh, really that I'm aware of. I have a large family, so we all kind of like figure it out, you know.
Resident	You sit in a group talkin' like that, most men are not comfortable with that.