NEBRASKA CANCER COMMUNITY HEALTH NEEDS ASSESSMENT

Hispanic Listening Sessions

November 2021

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EXECUTIVE SUMMARY

The Office of Community Outreach and Engagement at the University of Nebraska Medical Center's Fred and Pamela Buffett Cancer Center, in collaboration with the Nebraska Cancer Coalition (NC2) and with input from the Nebraska Comprehensive Cancer Control Program, is conducting a statewide cancer community health needs assessment during 2021. As part of the process, cancer centers and community organizations throughout the state were asked to help recruit cancer patients/survivors and caregivers to participate in a series of listening sessions. The listening sessions used a structured facilitation guide and poll questions to solicit participants' perspectives about the cancer journey as well as provide specific feedback on colorectal cancer screening awareness and participation.

Two listening sessions focused on perspectives of Hispanic community members. Participants in these listening sessions were open about the positive and negative aspects of their journey from cancer diagnosis through treatment. Knowing how to access available resources was a recurring theme, and participants shared resources with each other during the discussion. Participants identified barriers to cancer care including cultural attitudes, language, insufficiency of formal translation and interpretation services in some facilities, and the burden of competing financial and employment demands. The group highlighted the varied experiences of Hispanic women in terms of their knowledge of cancer, cancer resources, and their ability to navigate a complex medical system with differing levels of familiarity and access.

OVERVIEW

A 107-minute virtual listening session was held on June 10, 2021, with eight female participants from Omaha and Lincoln, recruited by the Center for Reducing Health Disparities at the University of Nebraska Medical Center (UNMC). The listening session consisted of two caregivers and six cancer patients/survivors. Cancer types represented included breast (n=4), thyroid (n=2), colorectal (n=1), and brain (n=1). Three participants were diagnosed with cancer in other states, and one continues to travel out of state for cancer treatment.

A 90-minute virtual listening session was held on June 16, 2021, with four rural Hispanic females recruited by the Center for Reducing Health Disparities at UNMC. One participant was from Lexington, one was from Grand Island, one from Kearney, and the fourth was from Holdrege. The group consisted of three survivors, two of whom were also caregivers (one's mother had died from cancer and another's husband had cancer). The fourth participant had been a caregiver to her husband who died of cancer. Cancer types represented included breast (n=3), colorectal (n=2), cervix (n=1), and lymphoma that spread to the spine and lungs (n=1). One participant indicated she was currently seeing a gastrointestinal specialist for liver testing but had not received a diagnosis. Care was received in Lexington, Kearney, Hastings, Grand Island, Lincoln, and Omaha, with some patients seen at multiple locations. Approximate travel to care was classified as local (n=2), nearby communities (approximately 30-45 minutes, n=3), 90 minutes (n=1), and 3 hours (n=1).

The listening sessions utilized a structured facilitation guide and included built-in polling questions administered verbally and via the “chat” feature in Zoom. Polls were used to assess overall community health status, cancer as a community health concern, and sources of cancer-related information. Discussion focused on people's experience with diagnosis and treatment as well as colorectal cancer (CRC) screening.

COMMUNITY HEALTH STATUS

Perceptions of the overall health of the community were mixed but generally negative. Overall, most participants thought the community's health was poor (33%) or fair (33%), with urban participants leaning more heavily toward poor (50%) and 75% of rural participants indicating fair (Figure 1). Only 25% of participants in either group rated the community's health as excellent. Regarding the importance of cancer as a community health concern, one urban participant did not have an opinion (“don't know”), but all of the rural participants and most (63%) of the urban participants believed it was very important (Figure 2). An urban participant further clarified that although cancer was an important issue in the community, “it's not mentioned that much.” A rural participant expressed a similar thought noting, “we have done very bad with the problem of cancer.”

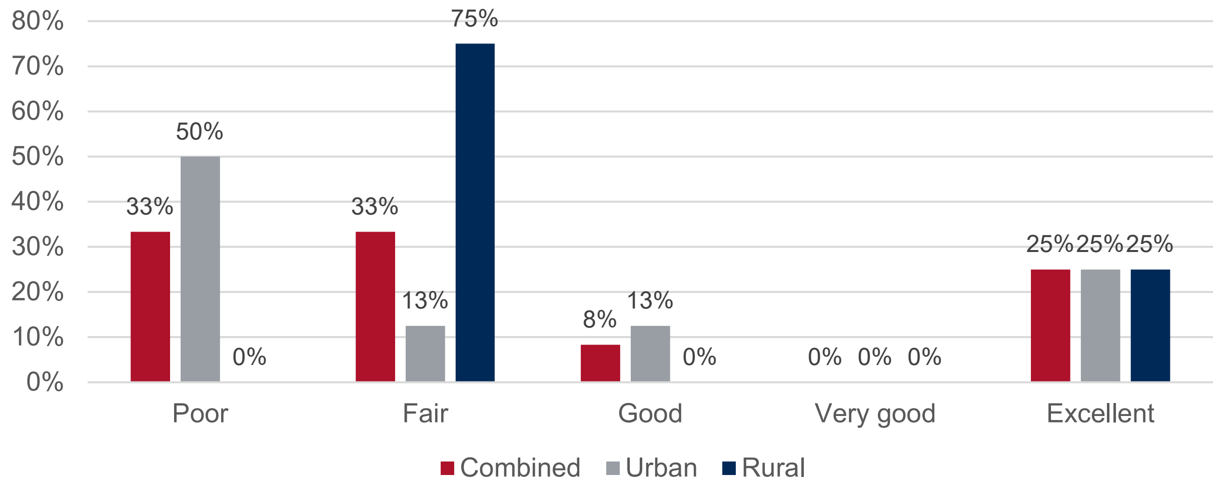


Figure 1. Overall health status of the community

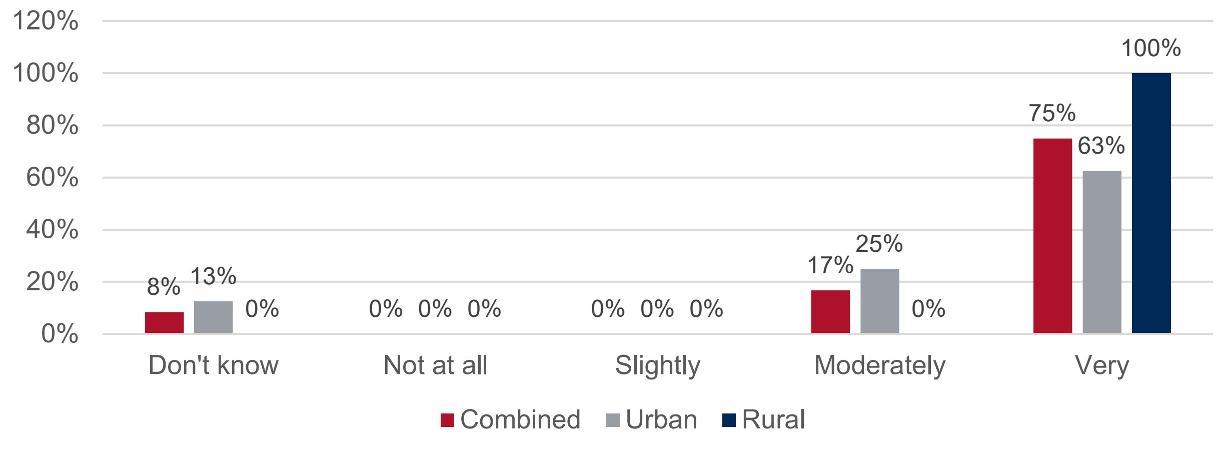
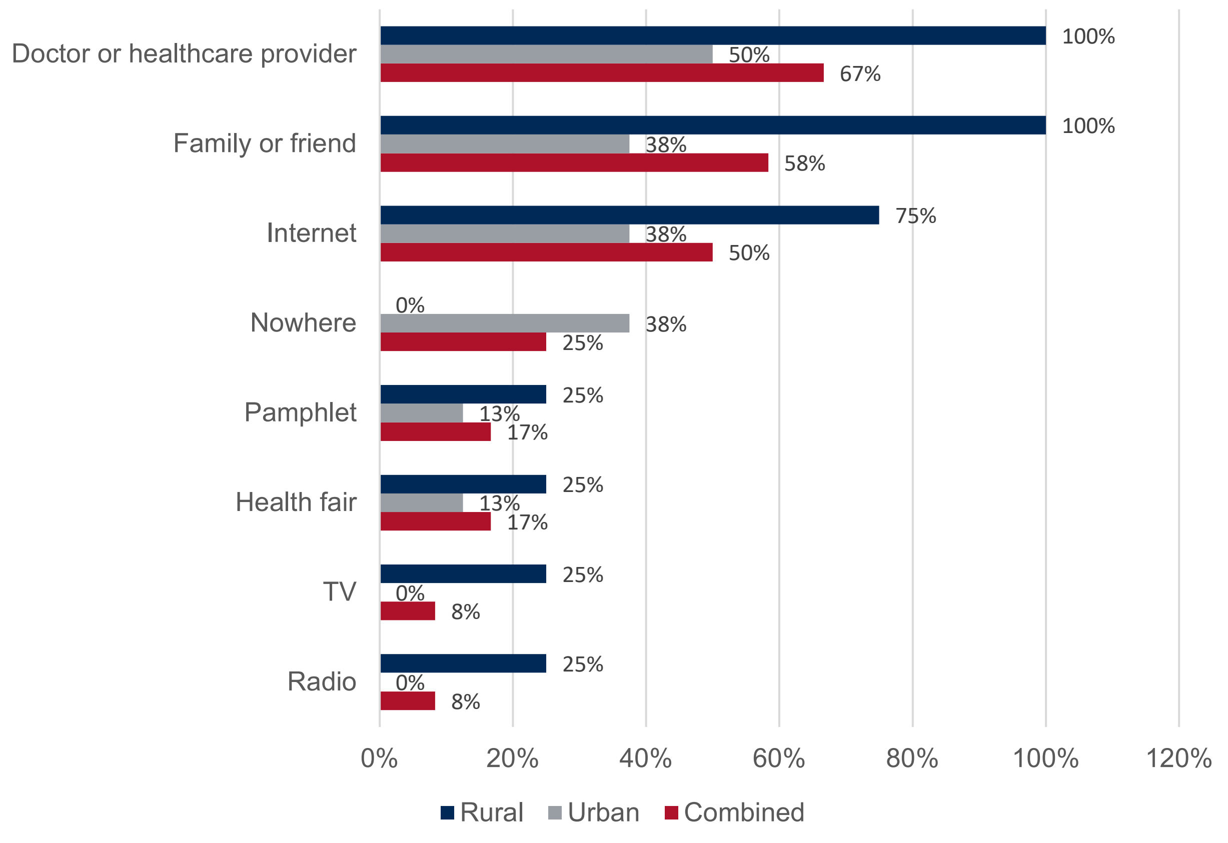


Figure 2. Importance of cancer as a health concern in the community

SOURCES OF INFORMATION ABOUT CANCER AND CANCER PREVENTION

Participants utilized a variety of sources of information about cancer, but the most commonly cited were the doctor or healthcare provider, family member or friend, and the internet (Figure 3). Other sources included pamphlets (such as tobacco control and prevention information) and health fairs. From the rural group, TV and radio were also mentioned. When asked to provide details about the sources of information, participants indicated that they have learned about cancer from family doctors and oncologists, community navigators, and the *Every Woman Matters* state cancer screening program, which is a federally-funded program that provides screening and diagnostic testing (including Pap tests, pelvic exams, clinical breast exams, age-appropriate mammography, and limited diagnostic tests) for medically underserved women aged 40-74. The program also provides public education and outreach. An urban participant indicated that she was a volunteer community health worker (*promotora*) at One World Community Health Center (One World) in Omaha where she received a lot of information as part of her training. One of the rural participants had also worked for *Every Woman Matters.* This participant was well-informed about cancer information and listed several information sources (fliers, health fairs, radio, TV).

Figure 3. Sources of information about cancer or cancer prevention



Note: Participants could select multiple responses

Participants in both urban and rural settings also learned about cancer through personal experience when a family member received a diagnosis. One rural participant started doing self-examinations and regular check-ups when her relative died from cancer. Two rural participants knew nothing about cancer until a close family member was diagnosed with cancer. One did not know what "cancer" meant when the doctor gave the diagnosis for her husband. Urban participants recommended talking to other people who went through the same things (i.e., cancer survivors and cancer support groups.)

Internet sources included searches of trusted sites such as WebMD, the American Cancer Society, and Mayo Clinic. Of the three rural participants who use the internet, they primarily use browsers to look up symptoms (not specific to cancer). Two also reported looking up information following doctor visits to learn about diagnosis and test results.

Of note, three of the eight urban participants indicated that they did not receive any information about cancer ("nowhere"), which was not one of original response options but has been added to the figure. None of the participants indicated the use of social media or newspapers, magazines or journals as sources of cancer information.

The most trusted source of cancer information varied. In the urban group, 40% indicated healthcare providers (including *promotores de salud*) as the most trusted source, 20% selected family or friend, 20% selected internet, and 20% said "none." All of the rural participants indicated that healthcare providers are the most trusted source of cancer information, although one participant also indicated that family members were highly trusted sources of information.

CANCER DIAGNOSIS AND TREATMENT

Cancer diagnosis can generally be grouped as self-identification of symptoms, discovering suspected cancer through routine medical care (e.g., annual check-ups or screening without symptoms), and being treated for symptoms that were not initially identified as potential cancer. In our listening sessions, several individuals self-identified symptoms although they did not necessarily suspect cancer was the cause.

In 2009, urban participant 8 (U8) from Omaha noticed a painful area of her breast. It had been 6 months since her annual gynecological check-up, at which time she had not had any symptoms. The day after she noticed the pain, she saw her gynecologist at "Regency" (Regency Methodist Physicians Clinic) and was sent to get a mammogram the same day. The mammogram had abnormal results, so she was referred for ultrasound at Catholic Health Initiatives (CHI) Lakeside. She was then referred to CHI Health Creighton University Medical Center—Bergan Mercy Hospital (Bergan Mercy) for biopsy and was diagnosed with stage 3 breast cancer (triple negative). Her treatment included a double mastectomy with chemotherapy.

U2 from Omaha had noticed a little ball in her throat but no discomfort. When she went to the doctor for a regular check-up at One World, the doctor "didn't take an interest" in what the patient was telling her about the lump but did refer the patient on to an endocrinologist who did further testing including an ultrasound, scan, and biopsy. She was referred to the Hope Medical Outreach program, which is an organization that coordinates care between volunteer physicians and community clinics (http://hopemed.us/about-hope/). She was diagnosed with stage 1 thyroid cancer and saw an oncologist at Methodist for surgery and radiation treatment.

U7 from Lincoln had a "sunken nipple" that she thought was related to milk production because her daughter was still little. She went to a clinic called Clinica del Corazon (Heart Clinic) because "it's free." Although she was working, she had not qualified for insurance yet. The clinic doctor referred her "to a clinic on Pioneer" in Lincoln where she received a mammogram and ultrasound that detected an abnormality. The Heart Clinic set up an appointment to review the results and the doctor informed her that she had "cancer, stage 3 with metastasis." She had many questions for the doctor, but he referred her to a surgeon from Bryan. She underwent mastectomy at CHI Health St. Elizabeth in Lincoln and radiation at Bryan Health in Lincoln. She also indicated that she received cancer treatment at UNMC.

When rural participant (R1) was three months pregnant with her second child, she discovered a little ball the size of a bean on her chest while she was bathing. She was receiving monthly prenatal care and mentioned the ball to her local doctor, who attributed it to pregnancy-related hormonal changes. The participant suspected she actually had cancer because her sister was dying from liver cancer at the time. The patient waited about a month and the ball got bigger, so she insisted the doctor do something. The doctor made an appointment for a biopsy, which came back negative. However, the participant continued to develop multiple large balls on her chest so she sought a second opinion and was informed of cancer. Because she had received conflicting results, she wanted a third opinion but “they didn’t want to do it anymore because…we had to beat time.” She was struggling because she was pregnant (she considered terminating) and her sister recently had died from cancer. She thought she would die from cancer as well but delayed treatment until a week after giving birth.

One participant’s (R4) husband had a pain with a little ball in the neck or throat area. He went to a specialist who prescribed medication. When the condition did not get better, the husband went back to the same doctor who informed him that he should get a biopsy. The husband was seen in Kearney and then sent to UNMC. The participant never suspected that her husband had cancer. He was diagnosed with lymphoma that had metastasized to the spine and lungs.

While living in Texas, one participant’s (R3) mother discovered a little purple ball coming out of her chest, which she treated with aloe vera. The mother recognized it as cancer because she had two cousins who were cancer survivors. The family took the mother to the doctor, but the surgery did not remove everything and the tumor grew. The doctors told R3, who was only 18 at the time, that her mother had a week left to live and she should “Take her home. There are too many people here.” R3 cared for her mother at home for another six months. R3 herself is also a cancer survivor. “I first started with my cervix, they removed part of my cervix due to cancer” which was treated locally. Later she had a chest biopsy in Hastings, which is where her oncologist was located.

Three other cancer patients/survivors had cancer discovered through medical care.

Sixteen years ago, U6 was living in Reno, Nevada. She accidentally found out she had breast cancer when she decided to get mammogram before getting breast implants. They discovered a tumor and ordered a biopsy. The patient wanted to “get rid of my breast, I’m not going to have children anymore” but the doctor said the tumor was small and could be surgically removed. She had surgery that confirmed cancer. She was then told she needed a second surgery to check the lymph nodes and was referred to an oncologist to receive “two chemos, and he did 45 radiations on me.”

U5 had been living in Louisiana. She was unable to conceive and underwent fertility treatment. She eventually had in vitro fertilization and gave birth to her daughter. Shortly thereafter, she had a mammogram and found out a few weeks later that she had breast cancer. Because she did not have insurance, she was denied treatment. She moved back to Nebraska and received free, excellent care.

R2 learned she had cancer through an annual physical exam. The doctor told her that she would have to have a CRC screening because of her age (older than 50 years). She did not want to have it because she thought she did not have cancer but she had some symptoms (swollen stomach, gas) so she decided to get the test done. She received the news over the phone about CRC cancer.

The remainder of participants described receiving a cancer diagnosis while seeking treatment for other medical conditions.

Five years ago, U3 was living in California and went on vacation to Mexico. While there, she went to a “routine checkup” with a healthcare provider due to symptoms of “feeling bad and vomiting” and passing out. The doctor suspected cancer and ordered an ultrasound to see if it was in the lymph nodes. When she saw the doctor again two weeks later, “the tumor had already grown very large” and she had immediate surgery. She later stated that she traveled to Mexico for the surgery because she did not have assistance in California. When she returned to California, she received radiation treatment because the cancer had spread. It has been four years since she was diagnosed; she is now experiencing liver problems and is scheduled for testing to see if the liver problems are side effects of the radiation treatments or if the cancer metastasized. This patient has lived in Nebraska for the past two years but continues to travel to California for follow-up care due to issues accessing and affording care locally. She stated that she searched for services in Lincoln but could not find them and that the cost here is too high. She went to the Centro de las Americas and was told that she had to be living in the state for 5 years to get residence before they could help her. She is planning to return to California “because here I have been denied all the help. Everything has been denied to me.”

A caregiver, U4, said that her husband had a severe heart attack last July and was admitted to UNMC. He started bleeding internally and remained hospitalized. In December 2020, he was diagnosed with stage 3 colorectal cancer.

Another caregiver, U1, reported that her husband’s symptoms began as a headache. At nights, he would report smelling as if someone was smoking near him but the smell would disappear when he was startled and then he would get a headache. He went to a clinic for six months and was told “your wife makes you come too much, you’re under stress.” Eventually he started seeing dots and went to an eye specialist who did an MRI – he was told he had a brain tumor. He then received radiation and removed the tumor in 2011. In 2017, the cancer came back and had metastasized. “The kind of radiation he needed was not available at Methodist” so he was referred to UNMC and receives chemotherapy at Methodist and radiation treatments at UNMC.

Themes related to the participants' experiences from diagnosis through treatment and maintenance are presented in Table 1 with selected quotations to illustrate concepts related to both positive and negative aspects of the themes.

Table 1. Positive and Negative Experiences with Cancer Treatment

Theme	Positive examples	Negative examples
Care coordination	• Patient navigator helped, and the cancer center "gave me this, this manual that I always carried with me" to keep track of tests, procedures, doctors' cards, and so forth." (U8) • "There are good places, what happens is that you have to be informed" about how to find and access them. (U7)	• Lack of doctors and long waiting period of 2-3 months. (U6) • "Because you have to see so many doctors … so many appointments, it can get out of control" and the lack of coordination leads to "unnecessary exams or tests and unnecessary expenses." (U8) • "I felt that at [1st provider] like they no longer want to take care of my husband" because he was transferred to [another provider] without explanation, but the [2nd provider] said the file was sent to him as a second opinion. The [2nd provider] continues to schedule chemotherapy appointments at the [1st provider]. "They do an exam here, they do an exam there, and they're not in coordination"; the patient receives chemotherapy and radiation treatments from providers in two different healthcare networks and "It's very complicated." (U1)
Patient-provider communication	• The doctors were very attentive; "Everyone would explain to me in a way that I would understand him and they would take their time" to make sure the patient and her husband understood. (U2) • Patient always requests an interpreter, "they support me a lot, and what I don't ask—they ask for me." (U2) • "As I am bilingual, I am on top of things asking for everything." "The nurse, the doctor has explained to me well." (R3)	• The patient used a recorder to record everything because although she is bilingual, "cancer" was confusing and sometimes she misunderstood what the doctor said. (U8) • Doctor did not take an interest in what the patient was saying about the symptom for thyroid cancer. (U2) • The staff at the hospital should be more sensitive. (U1) • When the patient received the cancer diagnosis, she was referred to a therapist who conducted the session via telemedicine. The therapist was very insensitive. The patient almost cried the way the therapist was talking to her. (U2) • Interpreting services don't work, particularly for those who speak a

		dialect. “You don't know how many times patients don't really understand what they're communicating and you have to interrupt and say, ‘That's not what the doctor said.’ You're not telling the patient what the doctor is really communicating--he's communicating. You have to intervene on behalf of those people.” (U4) • At cancer centers, all the doctors and staff are “Americans” and they do not speak Spanish; translation is even more difficult if a patient speaks a dialect. (R3) • Assigned to see assistant rather than specialist, but the assistant was unable to answer the patient’s questions and responded, “let me talk to the doctor” and went in and out of the appointment. (U1) • The patient had to rely on her young son to translate to learn about her husband’s cancer diagnosis. She did not know what “cancer” meant until the doctor left and her son asked if she understood. She said “no” so her son explained, “My dad can die.” The husband also did not understand the diagnosis until explained by the son. (R4) • Regarding balls in her chest, “I talked to the doctor, with the surgeon, and I told him that I wanted to have the DNA test done on me and they told me no.” “I have been looking, keep looking to get a second opinion, and I have not found a doctor. They tell me that there are no good ones here.” (R3)
Personnel	• “Thank God, we are in a place (UNMC) that has good doctors and there are very good programs.” (U7) • The endocrinologist (at Methodist) was very supportive. (U2) • “Nebraska welcomed in the best way, the doctors treated me very well.” (U5)	• “The doctor was very bad.” (U6) • Patient, caregiver, and interpreter all noted that staff at check-in “was treating us badly” because the patient forgot his ID card. (U1)

	• The male oncologist who is Hispanic is wonderful. (U5) • "A nurse navigator helped me." (U8) • The patient was well taken care of and the staff are friendly at the Cancer Institute in Grand Island (R3)	
Treatment	• Offered 6 free psychological therapy sessions (at Methodist). (U1) • Regardless of whether the patients had insurance or not, the patients were well treated. (U5) • "The doctor operated on me quickly." (R2) • Husband's radiation treatment "helped him a lot." (R4)	• Biopsy was very painful because tumor was attached with inflammation (and it seems she did not get anesthesiology). Her mastectomy was also very painful. (U8) • Chemotherapy pills were very expensive, and the patient could not afford it. (U1, U4) • Husband has "already received all [the radiation] the human body can handle" so radiation therapy was discontinued. (U1) • Patient wondered whether referral to multiple doctors, tests, treatments was because "the doctors…they want to make some money." (U6) • A long cut for surgery done in Kearney, but the patient later learned there were other options including a robotic surgery offered in Omaha. (R4) • The participant's husband suffered from severe pain; medications did not work. (R4)
Distance		• It was difficult with 30 radiations, the patient had to drive to get the treatment. (U7)
Support	• The patient received a lot of support from the doctors. (multiple participants) • The patient has been trying to help other patients who are going through the same thing because she is well informed and knows how it is like. (U7) • The patient took training to become patient navigator. (U8) • Spiritual support from church, God. (R1)	• There is a lot of help for women with cancer but not for men. (U1) • The participant was unable to tell her mother about her cancer because her mother was very old. The participant locked herself in her room and cried. (R2) • While participant's husband underwent cancer treatment, she "didn't have the support of anyone." (R4) • There is no service to educate people about how to cope with cancer. (R4)

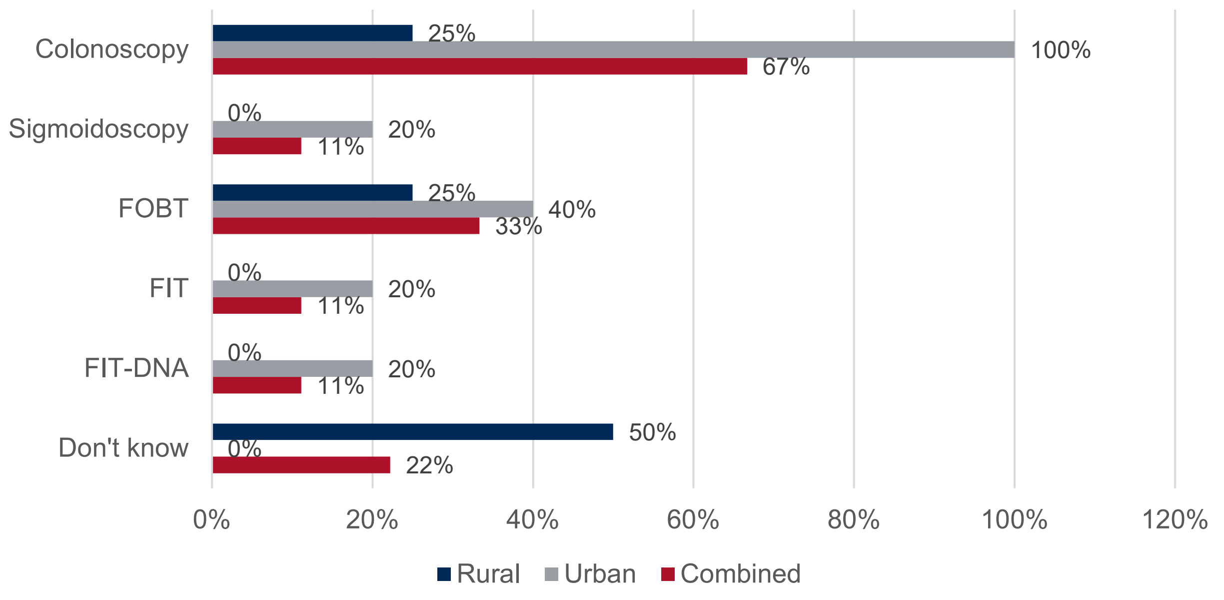
	• Hospice provided educational brochures about how to cope with husband's cancer. (R4) • Support from family. (multiple participants)	• "The most difficult thing for me…was having my child so young and feeling that I was leaving him, and I had another 7-year-old boy" whom she taught to care for himself. (R1)
Financial Support	• The hospital social worker (St. Elizabeth) helped her apply for Medicaid. When she didn't meet the 5-year residency requirement, the social worker told her "don't stress, bring all the medical bills here" and she would process them. The cancer center paid a month's rent and helped her with the bills (Lincoln). (U7) • The staff at One World helped the patient get financial assistance – the process was very fast. (U2) • After moving back to Nebraska, "from the first moment that I asked for help, the door was opened for me and I got all the help I needed." The hospital told the patient "It doesn't matter that you don't have insurance, we're not going to let you die. You're just like all people, very important." (U5) • For a patient with genetic breast cancer, Women's Hospital (Village Pointe) "gave…my whole family…all my siblings and my brothers' children to get genetics testing…for free." (U5)	• "Everything was denied to me" in Nebraska because the patient did not qualify for help due to residency requirements (she had been in the state less than 5 years) so she went back to Mexico and California for treatment. (U3) • "There are a lot of limitations for the illegal community… they don't have a social security number." (U1) • With or without insurance, obtaining chemotherapy pills is very difficult. "It is incredible to me that they leave that task to the patient instead of the doctors taking charge of that." (U4) • "The worst thing was that [in Louisiana] they told me that, since I had no insurance, they couldn't take care of me." (U5) • "When I got cancer, I stopped working" and applied for Medicare and Medicaid but was repeatedly denied. "Even though I had health insurance, they still charge you…coinsurance, copay and deductibles and all that. Besides medications." (R2)

An additional theme that emerged in both groups, that could not be categorized as positive or negative, was the participants' desire for complete surgical removal (radical surgery) of the cancerous organ (breast, thyroid, uterus) to make sure that the cancer did not return. This was expressed by the sentiment, "I'd rather be alive than to have cancer later" (R3). Participants indicated that the doctors often recommended less radical treatment (localized surgery).

COLORECTAL CANCER (CRC) SCREENING

Participants were asked what types of CRC screening methods they had ever heard about (Figure 4). Half the rural participants had not heard of any of the listed methods (e.g., colonoscopy, FOBT, FIT, etc.). Of those who had heard of CRC screening methods, colonoscopy and FOBT were the most commonly recognized methods. One urban participant indicated that she knew all the different types of CRC screening tests due to her relative's experience. Another urban participant mentioned familiarity with "the strips." This was presumed to be a fecal test, although the exact type was unspecified. Some clinics use at-home (mailed or received at clinic visits) FOBT tests as a first line screening due to cost and non-invasive nature of the test, so this may have been what the participant was referring to and it is recorded as such in the figure. This coincides with comments made by the rural participant who works for *Every Woman Matters*, who was well-informed about the at-home fecal test.

Figure 4. Colorectal cancer screening tests that participants had heard about prior to the listening session



Note: Participants could select multiple responses

Factors that impacted CRC screening (both positive and negative) are presented in Table 2. In addition to cultural factors, the realities of low-wage employment, often with lack of flexibility in work hours, impacts not only CRC screening but receipt of regular medical care in general.

Table 2. Factors that Impact CRC Screening

Theme	Example
Machismo	• “The Latino community is more closed minded and especially the men, they are very macho and don’t get those types of screenings.” (U7) • “Rooted traditionalism…that only concerns gay people…” (U5) • “Their ego of being male.” (U3) • “I feel that machismo also influence a lot…I am the man, I am strong, that doesn’t happen to me.” (R2) • “Unfortunately, Hispanics are very, very macho and they don’t want to get an exam of that kind.” (U5) • “My uncles, but as a joke, they say that they put them like a swab, stick with cotton and they introduce it by the rectum.” (R1)
Awareness	• Ignorance. (U1, U5) • Lack of information. (U1, U2, U5, U7, R2, R3, R4) • “We are very close minded.” (R4) • “We don’t give ourselves the task to search things up on the Internet.” (U2) • “They don’t know how to understand the information.” (U7) • On radio, misinformation may be communicated that negatively influences the community. Participant mentioned hearing a radio ad about free tests at pharmacies, but all pharmacies she contacted did not offer it. (U1) • The patient became more aware of cancer after she was diagnosed with cancer. (U2, U5) • “We need more education…getting medical exam every year.” (R2) • “The state of Nebraska has cancer screening campaigns where they distributed kits to do screening in their own home, but it is still not easy to give the kits to people, because they say that ‘No, I don’t need that.’” (R2)
Competing Demands	• “Not all people are up to date with checkups, we dedicate ourselves more to work…we start getting diseases, that’s when you start to worry.” (U5) • “They don’t want to lose work to get a medical exam…The day I miss work is the day I need to put food on my table.” (R2) • “Being careless about oneself” by not prioritizing “our own health…There is information, but many times we do not give it the importance, we do not look for the means.” (R1)
Fear	• “Cancer, oh...we’re scared.” (U2) • “Don’t want to go see a doctor because they don’t want to know a diagnosis.” (U7)
Help-seeking Attitudes	• People think “What a shame” but do not take action. (R3) • Denial – “I don’t have it.” (R3) • “Unfortunately, there are many people who say ‘oh no, this, I don't think it's going to happen to me either.’" (R4) • Only going to the doctor when feeling ill. “Oh, but I’m fine. I don’t have anything. I feel healthy.” (R2) • The doctor must tell patients forcefully or they will not do it. (R3) • “My uncles, but as a joke, they say that they put them like a swab, stick with cotton and they introduce it by the rectum.” (R1)

Barriers	• "In the community there are many barriers… financial (money, health insurance)…fear, shame, transportation...time." (R2) • "Many people do not have document so there is no insurance." (R3) • "Low resources for everyone." (R2, R3) • "The problem many times is that if you want to take a certain test, the insurances do not want to approve them, you have to do other processes before… After all, no, the insurance company is not going to want to pay…and that is where things also get delayed." (R3) • "I have met people who do not want to do [home tests] simply because it's the fact of using their excrement" even though it's free. (R2)

Participant suggestions for improving CRC screening included ideas for increasing public awareness of CRC through healthcare providers and facilities (Table 3).

Table 3. Suggestions to Improve CRC Screening

Theme	Example
Doctors	• "The doctor influences us a lot on how important this test should be." (U2) • "We don't' know…what the exam is like, but we're already making ideas in our heads…rather, they (doctors) have to explain to us so that we can understand what it is like and why it is important that we have to do it." (U2) • Educational programs where "they explain everything…in detail, like when do you have to go, and where do you have to go, all that." (R4) • "I do not have knowledge, but I would like to have a place where they could orient us, explain to us…in person and then later that would inform family and friends." (R1)
Clinic	• "In the clinic where I go, that's where I got all the information…The medical team, the oncologist, human resources…they have sent it to me via email. When I've been sitting there waiting…give me pamphlets." (U5)
Community Outreach	• A local organization in Grand Island (We Are GI) can spread the word. (R3) • Catholic Daughters of the Americas (Spanish) could host community presentations. (R3) • Church – the participant has 40 women who are educated about health topics. (R3) • "Giving brochures, going around like delivering at home…There are going to be meetings to explain. I think that would also help." (R4) • R1 disagreed and said "A lot of people don't read it, eh, they just take it and leave it" • "Group services…do meetings, do talks…send information to churches, schools, centers." (R2) • "I would like to do meetings, if I had the time." (R1) • Television, internet, social media "if educational messages are sent, they will see them." (R2)

COMMUNITY NEEDS AND SERVICES

Participants identified improvements needed in medical care, health education, and health promotion to be more sensitive to cultural and linguistic concerns faced by the Hispanic community, as well as improved provider-provider communication to lessen the negative impacts of fragmented care delivery. The rural group also mentioned the need for more bilingual healthcare providers.

- Sensitivity training for hospital staff. (U1)
- "Mandatory communication between all the doctors" - providers should be required to communicate with each other to coordinate care better. (U1)
- Need for professional translation and interpretation services, not just relying on community members to translate. ""I interpret a lot, but sometimes I run out of either Spanish, or the English…sometimes one does not find the right word to say it." (R3)
- Hospice services were all in English – "The did not give us an interpreter, nothing." (R3)

Participants identified a variety of needs within the community, including an emphasis on routine medical care and prevention and the need for more services and support for undocumented individuals. They also highlighted the need for health education that is accurate, reliable, and understandable.

- Need for general health education, not specific to cancer—"We lack medical education" about heart disease, diabetes, or "any disease." (R3)
- "Accessible clinics or hospitals for low-income people." (R2)
- "If a person is…earning the minimum, it is not enough for him, to put aside the children without eating, or the income without pay, to go to the doctor." (R2)
- Need for cancer support groups: There is no service to educate people about how to cope with cancer. (R4)
- Assistance should not be denied to people not here legally or to those who do not have a social security number. (U1, U3)
- Return the health fairs (South Omaha, Metro Community College, One World) to educate the community. (U2)
- Information is out there but community doesn't "know how to understand it." (U7)
- More cancer education in the community, such as in general hospital areas or pediatrician's offices. (U2)
- When doctor's do mention cancer screening, they need to provide more information to the patients so they can understand. A survivor related that her doctor recently told her "'Hey, you have to get breast cancer screening, because you are already at the age.' He just told me about it, but I don't know what else I have to do." (U2)
- Hispanic media (e.g., radio stations such as Radio Lobo, El Patron) talk shows are not always factually accurate, which "maybe, negatively affects the perception of Hispanic listeners." (U8)

Participants in the rural listening session also suggested specific messaging for their community, including the following:

- “Check yourselves” (and then follow-up with a healthcare provider) (R3)
- “Don’t think about yourselves, think about your family.” (R3)
- “Lose the shame…that a doctor looks at their private parts.” (R3)
- “Don’t leave it to time, because leaving it to time is what comes to harm” (get routine check-ups) (R1)

In addition to services, another identified need was the importance of having a sense of hope about a cancer diagnosis while realizing that cancer treatment is not a magic bullet and that there may be long-lasting side effects resulting from treatment. This idea was best expressed by the need for better explanations about the cancer recovery process, so patients know what to expect. The urban group also identified the need for emotional support throughout the cancer journey. This may be accomplished, in part, by additional survivorship care and support groups.

- Educate Hispanic community to overcome fear of diagnosis and cancer fatalism. (U7, R4)
- Better explanation about the cancer recovery process so patients know what to expect, that life is not instantly back to “normal”, and the “possible consequences and damage we may experience.” (U2)
- Seek support from family, friends, and the community. “Don’t stay alone…you get more depressed.” (R1)

CONCLUSION

Listening session participants appreciated the opportunity to share their experiences. These listening sessions highlighted the need for continuing efforts to address gaps in both general health care and cancer-specific care services including cancer support groups and colorectal cancer screening in Hispanic communities within Nebraska.