Two listening sessions were conducted among Latinx cancer survivors and caregivers in rural and urban Nebraska communities. Participants do not think the health of their communities is good (Fig 1). Cancer is an important health concern but “it’s not mentioned that much” and in rural areas, “we have done very bad with the problem of cancer” (Fig 2).

Most participants receive cancer-related information from healthcare providers, family or friends, and the internet. Promotores de salud and the Every Woman Matters (state cancer screening program) are important resources in both rural and urban areas. Women who had contact with Every Woman Matters were well-informed about cancer and cancer screening. In rural areas, health fairs, TV, and radio are also sources of cancer education.

Cancer Treatment Experience

Some community members do not know what “cancer” is, so the diagnosis may not be understood. Even for bilingual patients, “cancer” can be confusing, and patients may misunderstand what the doctor is trying to communicate. Formal translation and interpretation services are not always offered but are an important aspect of clear communication and patient advocacy. Medical interpreters can help identify when a patient is misunderstanding; “they support me a lot, and what I don’t ask—they ask for me.” “You don’t know how many times patients don’t really understand what [doctors] are communicating and you have to interrupt and say, ‘That’s not what the doctor said.’”

Cancer patients often see multiple doctors. Lack of care coordination leads to “unnecessary exams or tests and unnecessary expenses.” Patient navigators help address this problem. Hand-offs between providers need to be clearly explained to the patient. Many participants noted a desire for complete surgical removal (radical surgery) of the cancerous organ to make sure cancer did not return, stating “I’d rather be alive than to have cancer later.” Doctors often recommend less radical treatment (localized surgery), so clear communication, education, and shared decision-making are important.

Colorectal Cancer Screening

Factors leading to low screening rates include cultural attitudes (machismo) and treating the topic as a joke; general lack of awareness and information about colorectal cancer, the screening recommendations, and screening test options; competing demands (“not prioritizing our own health”); denial (“I don’t have it”); and economic factors such as cost, insurance, transportation, and inability to take time off work. To combat these barriers, “Explain to us so that we can understand what it is like and why it is important.” Spreading the word using community organizations was also recommended.