A listening session was conducted with self-identified LGBTQ+ cancer survivors from urban and rural Nebraska. Perceptions of overall community health were fair (Fig 1), with participants specifically identifying challenges with mental and spiritual health. Cancer is an important health concern (Fig 2), although it is only one of many concerns in the community. “There are also a whole lot of other things that are happening in the community that affect folks.”

Family or friends were the most common source of cancer information. Although only one participant received cancer information from a healthcare provider, all of them indicated doctors were the most trusted source of cancer information.

Cancer Treatment Experience

Experiences with diagnosis and treatment highlighted the importance of having a support person (friend, family, assigned navigator) advocate for the patient. Examples of advocacy included insisting on taking the patient’s symptoms seriously (not just prescribing pain medication), asking questions about diagnosis and treatment options, pushing for a second opinion when a provider’s actions seemed discriminatory, and writing the patient’s pronouns on the nursing board.

Participants were generally happy with the treatment facilities, although it was noted that rural areas had fewer options. Interactions with staff and providers set the tone for the overall perception of care. Some participants shared pointed examples of discrimination, but others reported positive examples of providers who were inclusive and accepting.

Colorectal Cancer (CRC) Screening

All participants had heard of colonoscopies, but there was limited knowledge of stool-based screening tests. Issues related to CRC screening included the need for education about the signs and symptoms of CRC and screening recommendations. Participants were unaware that the screening age now starts at 45 rather than 50 for average risk adults. Barriers to screening primarily centered on colonoscopies, including the bowel preparation, distance to facilities compounded by timing of the procedure (typically scheduled for early morning), and the perception that colonoscopies are treated “like it’s a joke…or they’re just seen as weird.”

Recommendations to improve CRC screening included information and awareness campaigns using social media (e.g., Instagram), community organizations, and workplaces. Messaging would preferably be delivered by people who have gone through the experience and share personal stories. De-stigmatizing and normalizing CRC screening were also suggested.

Recommendations

- General health education about the role of annual physical exams and preventive care
- Incentivize annual exams, associated lab work and screenings (e.g., $100 gift card)
- Sensitivity training for medical staff and providers to address discrimination, misgendering, multiple layers of identity, etc.
- Health care systems need a transparent accountability system so patients who experience poor treatment or discrimination know who to report to and what the process is.
- Increase support and advocacy for LGBTQ+ community in general