LGBTQ+ Cancer Care: Assessing the benefits and limitations of a novel cancer care coordination tool.

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Historically, members of the lesbian, gay, bisexual, transgender and queer (LGBTQ+) community experience significant disparities in cancer care outcomes.

These disparities stem from barriers to screening and care that include a lack of LGBTQ-competent providers, lack of health insurance, unstable housing, and the avoidance of care due to medical trauma and concerns about abuse and mistreatment within the medical space.

As certain cancers disproportionately affect LGBTQ+ people and disparities contribute to reduced rates of screening among this population thus leading to elevated risk of cancer diagnosis at later stages, optimum coordination of comprehensive healthcare for LGBTQ+ individuals merits prioritization.

Community Health Centers serve as critical providers of primary care to LGBTQ+ patients. However, once a patient is diagnosed with cancer and referred to specialty care outside the health center, primary care services are often disrupted or discontinued as a result of gaps in communication between primary and oncological care providers during the cancer care continuum (extending from screening and detection to treatment and survivorship).

Care gaps are most harmful to LGBTQ+ and other underserved patients who may lack the health information, economic resources and influence with health systems necessary to effectively manage inequities in cancer care.
The goal of this project is to address care gaps with a focus on the LGBTQ+ community in recognition of the urgent need to establish models and approaches that bolster more connected integration between primary care and cancer care delivery for the LGBTQ+ community and other underserved groups.

To address these care gaps, we adapted the **4R Oncology Model** - a novel patient-centric care coordination tool created to facilitate cancer planning - to serve as a longitudinal primary care checklist for patients and their care teams.

Project Goal
Three project aims:

- Conduct *qualitative research* alongside pilot studies of the 4R Care Delivery Model at Howard Brown Health Community Practice Care (CPC) sites
  - Identify *barriers and facilitators* to the implementation of the 4R model as a component of care delivered to LGBTQ+ cancer survivors
  - Use findings obtained at Howard Brown CPC sites to **refine and scale** the 4R Care Delivery Model in order to develop a broad protocol to be deployed nationally.
Semi-structured interviews were conducted with patients and caregivers (N = 9) and clinical care team members from Howard Brown Health and Northwestern Medicine (N=10).

Rapid Analysis Process, a qualitative analysis method recommended for use in circumstances in which a quick analysis is required to adopt changes to an ongoing process, was used to evaluate interviews.
Six neutral domain names were created and assigned to corresponding interview questions:

- Care Coordination/Communication
- Referrals/Supports/Resources
- LGBTQ needs
- Experiences Providing or Receiving Care
- COVID/Telehealth
- 4R Feedback

Next, transcript summaries were written for each interview.

Summaries were then transferred to a domain matrix (respondent x domain) to be assessed for similarities, differences and main takeaways across interviews.
Lack of communication between primary and oncological care exists and is commonly experienced by both clinical care team members and patients.

Electronic Medical Record (EMR) differences between health systems acts as a hindrance to improving communication across primary and oncological care.

Burden of communicating between primary and oncological care often falls on the patient.

PCPs hesitant to give patients feedback on cancer care, and patients deferring to oncologists for all questions, results in patients seeking primary care services from oncological providers.
Referrals/Supports/Resources

- Supports and resources available for patients often missed because they are not well integrated into care processes by clinical providers.
- Oncological care often misses the psychosocial realities of LGBTQ+ patients, resulting in a lack of referrals to behavioral and sociological health resources.
- Referrals to supports/resources are unfortunately frequently dependent on a patients’ health insurance and is thus limiting.
Among the LGBTQ+ patient population, there is a significant reliance on community and chosen family.

There is a need for an open acknowledgement of patients’ identities and how these identities, as well as their non-traditional support systems, may not be well represented or often visible in the medical space.

Provision of identity affirming practices (i.e. literature and resources specific to LGBTQ+ patients) is necessary for LGBTQ+ patients to feel welcomed and safe in medical settings.

Care teams must be accepting of patients’ social situations and must also document the richness of patient’s support network in their EMR.
Experiences Providing or Receiving Care

- Lack of information from specialists addressing the sexual health practices and needs of LGBTQ+ individuals leaves patients uninformed and feeling isolated from medical settings.
- Primary care and oncological care often struggle to address patients’ emotional health and may fail to recognize how emotional issues manifest in patients.
- Receiving a cancer diagnosis and suddenly having more people involved in one’s care leaves patients feeling overwhelmed and in need of someone to help navigate the cancer care process.
COVID caused a drastic decrease in patient engagement with primary care services. Successful transition to telehealth was largely dependent on patient's age and the severity/stage of the illness, such that younger and less severely ill patients experienced easier transitions to using telehealth. In some instances, telehealth limited the ability of clinicians to provide empathetic care. In other instances, telehealth via phone calls enabled patients to forego identity considerations, allowing for more freeing conversations on often taboo topics. COVID made it harder to access much needed social supports while also preventing support persons from accompanying patients to appointments, and thus created heightened feelings of isolation.
4R Feedback

- 4R has the potential to help patients mentally organize what their needs are and to know what is important to follow up on.
- Both patients and clinical care team see the value in 4R but believe it necessitates the input and help of a clinician to both fill out and ensure the accuracy and maintenance of the information.
- 4R can serve as a reminder for clinicians to check-in with patients about behavioral health needs and resources.
- Suggested improvements to 4R include reducing the amount of information on the tool to prevent feelings of overload and placing more emphasis on mental and emotional support resources.
Conclusions

- Safe and LGBTQ+ affirming care is critical to ensuring that appropriate and relevant information is provided to patients as they and their support systems consider new information that will affect their lives after a cancer diagnosis. Effective care coordination and the availability of appropriate resources can better ensure this type of care is provided.

- The 4R Oncology Model thus shows promise as a solution for initiating and sustaining more continuous communication between primary care and cancer care for LGBTQ+ cancer survivors. It also serves as a reminder for clinicians to address patients’ psychosocial needs via the provision and recommendation of behavioral health resources.
Next steps are to:

- Continue the identification and recruitment of LGBTQ+ patients, their caregivers and community organization representatives for semi-structured interviews.
- Use interviews to further elucidate the barriers and facilitators to cancer care coordination for this population.
- Demonstrate how iterations of the 4R model can lead to the development of a national protocol aimed at improving access to care and outcomes for the LGBTQ+ community and other underserved groups.
References


