

A Learning Health System Approach to Cancer Survivorship Care Among LGBTQ+ Communities

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QUESTION ASKED: What are barriers and facilitators to optimal care for lesbian, gay, bisexual, transgender, and queer (LGBTQ+) patients navigating the cancer care continuum and how might a novel, care coordination tool be used to improve cancer care for members of this community?

SUMMARY ANSWER: Positive and negative clinic-level patient-provider interactions, along with patient-provider and provider-provider communication throughout the cancer care continuum, represent barriers and facilitators to optimal care for LGBTQ+ patients. Cancer care coordination tools adapted to the specific needs of LGBTQ+ patients could improve care.

WHAT WE DID: In partnership with Howard Brown Health, researchers conducted qualitative interviews with LGBTQ+ patients, along with support persons, providers, and key stakeholders. Interviews aimed to elucidate patient experiences of navigating the cancer care continuum and to further garner feedback regarding a novel, cancer coordination tool, with careful attention paid to how such a tool might be adapted to best address primary and oncology care needs of LGBTQ+ patients. A multistage analysis process was conducted, wherein thematic codes were developed by members of the research team. A final codebook was developed, and qualitative interviews were conducted until thematic saturation was reached.

WHAT WE FOUND: Adverse clinic-level experiences driven by a lack of LGBTQ-competent care, along with

limited patient-provider and provider-provider communication, represent barriers to optimal care for LGBTQ+ patients navigating cancer diagnosis. Care coordination across institution and specialty, specifically between primary and oncology care providers, is inconsistent and often places the responsibility of coordination on the patient. Positive clinic-level experiences stemming from LGBTQ-competent care and efficient patient-provider and provider-provider communication contribute to optimal patient care. The studied cancer care coordination model further shows potential for adaptation to address needs unique to LGBTQ+ patients with cancer.

BIAS, CONFOUNDING FACTORS, DRAWBACKS: The LGBTQ+ community is not homogenous. As such, it is important to acknowledge that although some experiences are shared, those of one individual or sample may differ from the next. Furthermore, although the cancer care coordination tool examined in this study showed potential to improve care for LGBTQ+ patients with cancer, care coordination is not a total solution to mitigating disparities affecting LGBTQ+ patients.

REAL-LIFE IMPLICATIONS: This study highlighted the importance of LGBTQ-competent care, resources, and care coordination for LGBTQ+ patients navigating the cancer care continuum. Identified shortcomings in communication and coordination between primary and oncology care services must be further explored and addressed to improve care delivered to LGBTQ+ patients.

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abstract

PURPOSE Lesbian, gay, bisexual, transgender, and queer (LGBTQ+) individuals who receive primary care services at community health centers are often referred to external specialty care centers after cancer diagnosis, upon which primary care services are disrupted and may be discontinued because of gaps in communication between primary and oncologic care providers. This qualitative study evaluated barriers and facilitators to effective care coordination for LGBTQ+ patients with cancer and the utility of a novel cancer care coordination tool to mitigate identified barriers.

MATERIALS AND METHODS Semistructured interviews with LGBTQ+ cancer survivors, caregivers to LGBTQ+ persons, clinical team members who provide care to LGBTQ+ patients, and members of community-based organizations that work with LGBTQ+ patients were conducted. Interview analysis was a multistage process, wherein a constant comparison approach was used. Transcripts were reviewed and coded using Atlas.ti Cloud.

RESULTS A total of 26 individuals were interviewed: 10 patients, four caregivers, 10 clinical care team members, and two community organization representatives. Interview analysis yielded insight regarding (1) LGBTQ+ patient experiences engaging with primary and oncologic care at the clinic level and (2) perceptions of patient-provider and provider-provider communication and coordination.

CONCLUSION Interview findings indicate a need for further development of interventions aimed at improving care coordination, patient experience, and outcomes in the cancer care continuum for LGBTQ+ patients. Learning health systems, like the one studied, show great potential for contributing to the development of such interventions.

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INTRODUCTION

Members of lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities experience health disparities stemming from factors that include barriers to access, such as lack of LGBTQ+-competent providers, discrimination, avoidance of care because of concerns about abuse and mistreatment, low income, and unstable housing.^{1,2} Such health disparities affecting LGBTQ+ communities may additionally be under-evaluated as a result of nonuniversal collection of sexual orientation and gender identity (SOGI) data.³ Although the Affordable Care Act, for example, expanded health insurance coverage to millions of Americans, including those within the LGBTQ+ community, assessing the actual rates of insurance coverage among the LGBTQ+ community remains difficult as SOGI data

collection is not yet universal and is inconsistent in federal and state data sources.^{1,4} This lack of universal SOGI data collection contributes to a still-limited understanding of the full breadth of health disparities experienced by LGBTQ+ individuals.

What is known, however, is that current barriers contribute to reduced rates of preventive screening among LGBTQ+ individuals, which may lead to diagnosis at later stages of cancer, affecting survivorship experiences and outcomes. LGBTQ+ individuals with cancer are at elevated risk for a number of comorbidities that include mental health conditions, substance use disorders, smoking-related diseases, cardiovascular disease, and HIV.^{2,5,6} Members of the LGBTQ+ community are more likely to depend on one another in informal, unpaid caregiving relationships; in

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addition to creating high caregiver burdens, these relationships may be unrecognized and invalidated by formal medical care systems.⁷⁻⁹

Exacerbating cancer disparities faced by LGBTQ+ communities is a breakdown in care between primary and oncology care teams, which often occurs upon diagnosis of cancer. Although primary care in community health clinics is crucial for the health of LGBTQ+ individuals and other underserved groups, patients navigating cancer diagnosis must often seek oncology care outside these more familiar settings. More than 70% of cancer patients' care is initiated at primary care sites, but primary care providers (PCPs) generally refer new patients with cancer to oncology providers who are often off-site and institutionally disconnected from the patient's primary care medical home or community practice care site (CPC).¹⁰

Once cancer is diagnosed, care at the CPC is typically markedly disrupted or even discontinued. This leaves a large gap in integrated primary care services for patients, particularly those dealing with comorbid conditions such as diabetes and depression. Primary and cancer care physician practices tend to exist in silos, and expectations for how patient needs are prioritized and how provider roles are distributed are often communicated and coordinated poorly.¹¹⁻¹⁴

Despite CPCs' strength in providing essential wrap-around services, access to these services typically diminishes upon referral to oncology care practices that are generally not prepared to take up the breadth of issues managed by CPCs.¹⁵⁻¹⁷ Thus, at the point of cancer diagnosis, patients often become vulnerable to disruption in care and support systems. Such care gaps are especially harmful to LGBTQ+ and other underserved patients who may lack the health information, economic resources, and influence with health systems necessary to effectively manage fragmentation in primary and cancer care. Additionally, as LGBTQ+ patients are more likely to seek primary care from community health centers (CHCs), CHC providers must work as a team with oncology and other specialty providers to deliver comprehensive care and avoid fragmentation that can occur upon cancer diagnosis. The management and delivery of interdependent care, where timing and sequencing of care is important for outcomes (eg, a visit to a PCP to discuss chronic disease management, such as diabetes, before and during cancer treatment), proves to be particularly challenging.

The 4R Oncology Model (4R; Right Information and Right Care for the Right Patient at the Right Time) is an evidence-based intervention that aims to address gaps in care coordination, patient-clinician communication, and other breakdowns in health care delivery across primary, oncology, and specialized care.¹⁷ The model was developed as a mechanism to facilitate teamwork and team-based care delivery and coordination, especially across multi-institution clinical teams.¹⁸ 4R uses project management to plan and manage care interdependencies across care

team members, assign clear responsibilities to care team members and the patient, and designate a quarterback function to lead the care team across the oncology, primary, and specialized care continuum. The 4R model, a patient-centric care project plan, explicitly outlines the sequencing, timing, and care team member/patient responsibilities for interdependent tasks, and is updated as needed. This systematic approach helps to orchestrate complex care of patients with cancer with comorbidities and prevent breakdowns. By sharing a paper copy of the project plan, including updated versions, so that the patient and their caregiver can be fully informed and confidently voice concerns, the 4R model supports patient and caregiver agency during care.

In a prior study, use of 4R by patients navigating care for breast cancer improved the receipt of PCP services and contributed to more effective delivery of care outside the cancer center setting. 4R was found to be particularly helpful for patients receiving care in safety-net settings.¹⁷ The 4R Oncology Model proved to be an effective tool for coordinating interdependent, time-sensitive care between oncology and primary care settings. 4R represents a unique cancer care coordination model for its emphasis on systematic management of interdependent care across specialties and organizations and its facilitation of teamwork beyond multidisciplinary clinics or conferences within cancer centers.¹⁹⁻²⁷ Effective, coordinated care and teamwork must occur longitudinally over the course of a patient's care continuum.²⁸⁻³⁰ 4R has proven effective for facilitating this type of care, while also contributing to patients' care-management abilities.

As a component of the model, the 4R care plan, called Care Sequence, serves as a learning health system whereby processes of care can be improved through iterative refinements to the care plan. A learning health system, as summarized by Simon et al,³¹ is an infrastructure-supported health care system wherein data produced from patient-centered care are first available, and then continuously analyzed to optimize clinical decision making and best practices for real-time, constant process improvement. A learning health system approach centers patient feedback in process improvement, and as such contributes to safer, more efficient care that is responsive to changing patient needs.^{31,32} The 4R Care Sequence embodies such an approach in its capacity to undergo iterative change on the basis of patient feedback and thus center the individual throughout the care coordination process. The parent study of this qualitative research analysis has an effectiveness-implementation hybrid design allowing investigation of the implementation of the 4R care delivery model as well as its effectiveness.³³

The 4R model has shown great potential to improve team-based care, including coordination between patients and clinicians, within clinical teams, and between clinical teams.^{17,34} Among a growing body of literature surrounding team-based medicine, care coordination, and cancer, few studies have addressed such subjects as they specifically

pertain to LGBTQ+ communities. As such, the current study's analysis of 4R's potential to improve care specifically for LGBTQ+ individuals, who face identity-specific barriers and disparities in navigating cancer diagnosis and survivorship, provides critical evidence in support of its use to address cancer health inequities in this population.

This qualitative study aimed to elucidate barriers and facilitators to optimal care for LGBTQ+ patients along the cancer care continuum. Interviews assessed the applicability and potential impact of 4R to LGBTQ+ communities.

MATERIALS AND METHODS

Study Design

Qualitative methods, such as interviews, are valuable for collecting personal experience and insight that solely quantitative studies would otherwise miss.^{35,36} Our study team conducted individual interviews with LGBTQ+ patients with cancer and LGBTQ+ cancer survivors, caregivers to LGBTQ+ persons, clinical team members who provide care to LGBTQ+ patients, and members of community-based organizations that work with LGBTQ+ patients, to understand experiences of care and care coordination and adapt the 4R model to the unique needs of cancer patients and survivors in LGBTQ+ communities. Leveraging our team's past work in qualitative methods,³⁷⁻³⁹ along with partnerships with organizations serving LGBTQ+ communities, our study team developed interview questions aimed at identifying barriers and facilitators to care and care coordination between primary and oncology care for LGBTQ+ individuals. The study team created four interview guides (one for each participant type) and included analogous topics with questions specific to each participant's role in cancer care. See [Table 1](#) for sample items from the qualitative instrument.

Study Setting

Participants were recruited from a local academic medical center and Howard Brown Health, a Federally Qualified Health Center system that provides gender- and identity-affirming primary care and behavioral health services to LGBTQ+ patients. As a trusted organization among LGBTQ+ communities in and around Chicago, Howard Brown Health (HBH) is an agency that delivers health and social services to more than 40,000 adults and youth. Within the cancer care continuum, HBH provides cancer screening and prevention services to its patients. Upon cancer diagnosis, HBH connects patients with external organizations for oncologic and specialized services.

Recruitment and Data Collection

Aiming to create a comprehensive understanding of cancer care coordination, we recruited LGBTQ+ patients, caregivers or support persons, clinical care team members, and representatives of community-based organizations affiliated with the care of LGBTQ+ patients, to participate in this study. Patients eligible for study participation (1) had a

diagnosis of cancer (2) were age 18 years or older, and (3) self-identified as LGBTQ+. Other study participants, including clinical team members, caregivers, and representatives of community organizations recruited for participation, were (1) age 18 years or older and (2) provided care or support to LGBTQ+ person(s).

Research staff at HBH identified eligible patients via medical records and contacted them to offer participation. Patients who expressed interest were then contacted by the Northwestern research team to schedule an interview. Recruitment flyers were also disseminated across HBH sites. Snowball recruitment⁴⁰ was additionally used to identify other patients and/or caregivers potentially interested in study participation. Clinical care team members and community organization representatives were identified for study participation by leveraging current professional networks at HBH and Northwestern Medicine. Snowball recruitment methods were again used at the conclusion of interviews to recruit other clinical care team members and community organization representatives.

Approval was obtained from the Northwestern University and Howard Brown Health Institutional Review Boards to conduct this study. Between July, 2021, and March, 2022, two research assistants (W.D. and N.A.) conducted interviews with patients, caregivers, clinical team members, and community organization representatives. Interviews were conducted via Zoom or telephone and included one research team member and one participant. Verbal consent was obtained at the start of each interview. Questions assessed participants' personal experiences navigating the cancer care continuum, and careful attention was paid to the role that each participant's unique identity played in such experiences. The entire interview had a foundation of asking about LGBTQ+ experiences. All interviewed patients self-identified as LGBTQ+, and the patient interview script began with, "Our team is working with Howard Brown Health to understand more about how to improve cancer care coordination for LGBTQ patients. I wanted to talk with you today to hear about your experiences after having received a diagnosis of cancer." We intentionally avoided asking leading questions that could potentially encourage connections and experiences that study participants themselves did not see, to allow participants the space to express how they felt. All interviews were audio-recorded and later transcribed using Temi, a web-based transcription service. Average interview time was 30-45 minutes. After each interview, participants were sent a brief demographic survey and compensated with a \$50 in US dollars VISA gift card.

Data Analysis

Interview analysis was a multistage process, using steps outlined by Strauss and Corbin.⁴¹ A constant comparison approach was used, whereby deductive codes were supplemented by inductive coding to create an iterative qualitative analysis process to incorporate emergent themes. Members of

TABLE 1. Qualitative Instrument

Category	Patients/Caregivers	Stakeholders
Experience providing and receiving care	After you found out about your diagnosis of cancer, what was it like for you to figure out the next steps? What has been your experience in receiving primary care services once you were diagnosed with cancer?	What are important considerations that you found should be accounted for when providing cancer care for LGBTQ+ patient populations? What has been your experience in providing primary care services for your cancer survivor patients?
Care coordination and communication	Did you feel like your health care providers, including primary care, oncologist, or other specialists, all knew what was going on with all parts of your care?	What are some ways that you think communication with oncology and subspecialty care could be improved? How is the patient's primary care team informed of the care received by oncology and subspecialists?
Referrals, supports, and resources	Were you given referrals for support or resources? What was your experience like in getting connected to those resources?	What types of supports and resources do cancer survivors have access to at your clinic?
COVID-19 pandemic/telehealth	How has the COVID-19 pandemic affected you getting the care and support you need? Have you received any care using telehealth?	How has the COVID-19 pandemic changed the care of patients with cancer in your clinic? How has the transition to telehealth been for you as a provider?
4R feedback	Would using a form like this be helpful for you? Why or why not?	What would make this form more useful to you and your patients?

Abbreviations: 4R, Right Information and Right Care for the Right Patient at the Right Time; LGBTQ, lesbian, gay, bisexual, transgender, and queer.

the research team (W.D., N.A., and S.D.) created an initial, open codebook using structural coding to identify codes from initial interview questions. Thematic coding was then used to refine existing codes and identify new ones through the review of two randomly chosen interview transcripts. After the two transcripts were reviewed and a second codebook developed, team members discussed and refined the codes further. The resulting codebook was then scrutinized again through its application to two additional, randomly selected transcripts. The final codebook was then discussed and solidified with group consensus. This codebook was then applied to all transcripts. Axial and selective coding processes followed. Each transcript was reviewed by two team members using Atlas.ti Cloud. Discrepancies in coding were resolved through group discussion between all coders, and two broad themes were ultimately developed for the organization of results. A code meaning approach, as outlined by Hennink and Kaiser,⁴² was used to assess thematic saturation; interviews were analyzed one by one until subsequent interviewing provided no additional insight, nuance, or new understanding of established codes. Qualitative interviews were thus conducted until this point of thematic saturation, as defined in the code meaning approach.

RESULTS

A total of 26 individuals were interviewed: 10 patients, four caregivers, 10 clinical team members, and two community organization representatives. All participants were included in this analysis. Sociodemographic characteristics of the 26 participants, stratified by patient/caregiver and clinical care team member/community organization representatives, can be found in [Table 2](#).

We now report key qualitative research findings, organized around two prominent themes identified by patients, caregivers, clinical team members, and community

organization representatives. These themes can broadly be categorized as (1) LGBTQ+ patient experiences engaging with primary and oncologic care at the clinic level and (2) perceptions of patient-provider and provider-provider communication and coordination ([Table 3](#)).

LGBTQ+ Patient Experiences Engaging With Primary and Oncologic Care at the Clinic Level

The impact of gender- and identity-affirming care and trust.

Many study participants discussed the importance of gender- or identity-affirming health care. Components of gender- and identity-affirming care that emerged in interviews included providers' respect for patient SOGI, use of correct pronouns, cognizance of medical trauma, creation of a safe space, and dedication to listening to patient concerns. Although gender- and identity-affirming care was not always standard for patients, it was very impactful when present.

The burden of seeking out gender- and identity-affirming health care almost entirely fell on patients. Several patients spoke about the lengthy search process they undertook to find PCPs, and especially oncologists, who they felt could provide gender- and identity-affirming care. One patient reflected on this search process after being referred to an oncologist by their PCP: "So the person that they had referred me to had never seen a trans patient in all the time that she had been there. So it was back to [my primary care provider], and [...] she was able to finally get me two names of people. So I went to meet with [one of them], and he's like amazing." This example supports the importance of engaging patients as central care team members active in the decision-making process so that they are comfortable voicing concerns if care is not adequate. However, this responsibility should not only be placed on patients. With many LGBTQ+ patients having had adverse experiences in health care settings because of discrimination, bias, and

TABLE 2. Participant Demographics, Stratified by Group

Participant Characteristic	Patients/Caregivers, No. (%)	Stakeholders, No. (%)
Age, years		
25-44	6 (42.8)	9 (81.8)
45-64	4 (28.6)	2 (18.2)
65+	4 (28.6)	—
Education level		
Some college	6 (42.8)	—
College (4 years or more)	9 (64.2)	11 (100)
Health insurance type		
Public (Medicaid/Medicare)	4 (28.6)	—
Private (employer/marketplace)	10 (71.4)	—
Race/ethnicity		
White	12 (85.7)	11 (100)
Black/African American	2 (14.3)	—
Asian or Pacific Islander	—	1 (9.1)
Hispanic/Latino	1 (7.1)	—
Sexual orientation		
Lesbian	1 (7.1)	—
Gay	7 (50)	—
Bisexual	3 (21.4)	—
Queer	2 (14.3)	—
Straight	1 (7.1)	—
Gender identity		
Male/man	8 (57.1)	3 (27.3)
Female/woman	3 (21.4)	7 (62.6)
Trans-male/trans-man	1 (7.1)	—
Genderqueer/nonconforming	2 (14.3)	1 (9.1)
Sex assigned at birth		
Male	8 (57.1)	—
Female	6 (42.9)	—

the absence of gender- and identity-affirming care, increased teamwork between and within clinical teams could potentially help patients find appropriate care.

4R as an identity-specific and culturally responsive tool.

Participants appreciated the 4R Care Sequence's intentional specificity to individuals with LGBTQ+ identities. This general feedback stood in contrast to one particular patient's experience with other care coordination forms they had received from their oncologist. In recalling one form they received, the patient elaborated, "It was basically a handout [...] of what to expect week by week. [...] there was certainly some effort that was put into it, but it wasn't personal, personalized, and it certainly wasn't written for a gay man." Participants also appreciated the 4R Care Sequence's inclusion of external

resources and community-based organizations that offered LGBTQ+-inclusive or focused resources and services.

A few participants also noted 4R's potential to empower them as they navigated their own cancer care, a journey where they often felt powerless. One patient reflected, "When you're diagnosed with cancer, you feel like you've lost control of your body. So control is out the window. [...] If you can't control your body, you can't control anything. You know that was big. So I think, for me personally, this [4R Care Sequence] would have gone a long way in making me feel a little bit more in control of that situation." Interviewed participants appreciated the 4R Care Sequence's ability to engage patients as central members of the care team and further help them learn to better navigate their care.

Perceptions of Patient-Provider and Provider-Provider Communication and Coordination

Patient-provider communication and patient and caregiver agency.

Generally, participants felt positively about communication between patients and the clinical care team. Notably, opinions among patients varied regarding with which of their providers (primary care vs oncologic care) they communicated more frequently and meaningfully. Several patients alluded to relying more heavily on their PCPs for communicating concerns and questions related to their cancer treatment or other health needs. These patients often mentioned that their PCPs were more effectively able to explain the ongoing processes of their care. Patients also referenced their longitudinal relationships with their PCPs as contributors to their tendency to defer to them for insight.

Alternatively, several patients communicated more frequently with their oncology providers throughout their care. As one patient recalled, "...because I was so vulnerable. I completely trusted them. Unbeknownst to me. I didn't even realize that's what I was doing. I completely trusted them and followed their guidance on everything and everything they told me to do. [...] if I had questions, they were definitely there for me to reach out to contact and to ask whatever I wanted." Faced with a frightening cancer diagnosis that often occupied most of their focus, patients often felt it necessary to defer to their oncologists whenever questions or concerns regarding their health and treatment arose, even if those questions fell within the realm of primary care. Patients also reflected that they felt their oncology providers, who commonly worked out of more well-resourced care centers, had more bandwidth to respond quickly to their questions and concerns; many patients highlighted the role of nursing teams as integral to their communication with their oncology providers.

Provider-provider communication and patient and caregiver agency.

Although communication between patients and providers was generally viewed positively, perceptions regarding communication between providers, notably between patients' primary care and oncology providers, were less favorable. Communication and coordination between

TABLE 3. Interview Themes, Subthemes, and Exemplar Quotes

Theme	Subthemes and Exemplar Quotes
Clinic-level experiences with primary and oncologic care	<p>Gender- and identity-affirming care and trust</p> <p>“I think the unknown was so unknown, or the extent of what was going to happen was so unknown. It felt like it was very much not related to me as a gay man, what to expect.” (PT)</p> <p>“Given my experience with her, being kind of like, super not trans-informed. I didn’t really like trust her recommendations.” (PT)</p> <p>“I think something that we’re seeing that comes up frequently in the support groups as a discussion topic is health care trauma, mistrust of the health care community. A greater, systemic discrimination that’s really tainted, I think a lot of our client’s perception of health care providers and health care centers.” (CT)</p> <p>“As far as commonalities that I’ve noticed so far, the biggest one seems to be the issue of representation. So do [patients] feel represented in the education they’re receiving about their care, about their treatment, about quality-of-life issues, and long-term survivorship, and what that might mean in the context of that identity.” (CT)</p>
	<p>Provider search process</p> <p>“So the person that they had referred me to had never seen a trans patient in all the time that she had been there. So it was back to [my primary care provider], and [...] she was able to finally get me two names of people. So I went to meet with [one of them], and he’s like amazing.” (PT)</p> <p>“I’ve gone through a string of primary care physicians, none of whom seemed supportive of, I wouldn’t call it LGBT lifestyle, but specifically bloody lifestyle — that I’m polyamorous and have multiple ongoing romantic partners. And as part of that, I get STI testing every three months [...] and every primary care physician that I would find through [my insurance] would eventually start to, give resistance, until I started just using [Howard Brown].” (PT)</p>
	<p>4R and patient/culture responsiveness</p> <p>“I think especially immediately after the diagnosis, I did feel very powerless. And very much like nobody could give me information and I didn’t know what information I needed [...] [My doctor] said, “you have cancer” and the world stopped for a second, but he kept talking.[...] I have no idea what I’m supposed to know at this point. [...] You know, so I think having [4R] to be able to go back and look at, to have [...] something to physically hold on to that has information would have made me feel a little bit more in the driver’s seat of what was happening and given me a little bit more control over myself. And that was a big thing. Because at that point, when you’re diagnosed with cancer, you feel like you’ve lost control of your body. So control is out the window. You feel like you have no control. If you can’t control your body, you can’t control anything. [...] So I think [4R] would have gone a long way in making me feel a little bit more in control of that situation.” (PT)</p>
Communication and care coordination	<p>Patient-provider communication</p> <p>“They were very much on top of everything. [...] because I was so vulnerable, I completely trusted them. Unbeknownst to me. I didn’t even realize that’s what I was doing. I completely trusted them and followed their guidance on everything. And everything they told me to do, I did. So if I had questions, they were definitely there for me to reach out to contact and to ask whatever I wanted.” (PT)</p>
	<p>Provider-provider communication</p> <p>“I don’t think there was conversation between my primary and surgeon [...] I felt like it was certainly something that I had to orchestrate, that I had to advocate for myself.” (PT)</p> <p>“I mean really when it comes down to it, a lot of what falls through the cracks, it’s just a simple lack of communication. I should say an effort to communicate.” (CT)</p> <p>“Most of my really big difficulties seem to be when I was trying to get information and things coordinated between [different institutions]. [...] if I had to go between systems, it was like ‘ahhh.’” (PT)</p> <p>“I just needed somebody to walk me through the steps. Because when you get a diagnosis like that, all of a sudden, there are more people involved in your care, and no two facilities seem to handle that kind of thing exactly the same way. And I just felt like I spent a lot of time going: ‘Did I miss something?’ ‘Am I doing this right?’ ‘Was I supposed to do something else?’” (PT)</p> <p>“If their primary care doctor is outside of [our] network, there’s a very good chance that there won’t be any communication between the doctors [...]. I would have to say that communication between doctors outside of the network is very rare.” (CT)</p> <p>“I spent a lot of time like trying to get people on the same page and trying to get, you know, lab reports from this office to this specialist. It was very frustrating.” (PT)</p>
	<p>Referrals</p> <p>“I think we historically have struggled with making sure that our internal providers are aware of the kind of behavioral health of support options for folks with cancer diagnoses.” (CT)</p> <p>“I hope that [my doctor] sees that this is [necessary] for him to be even more successful. He needs to have [behavioral health] incorporated into his care... it certainly could have been 100% more helpful if it happened before my surgery and leading up to it.” (PT)</p>
	<p>4R and care coordination</p> <p>“I could see [4R] being useful. It’s hard to know how it might go from patient to patient, but sometimes what’s missing for folks as they move through treatment is this bird’s eye view. It’s easy to feel overwhelmed by all of the pieces because so many of them are not connected and very separate. So this could be a great way of organizing it.” (CT)</p> <p>“I like [4R] as a checklist of like, ‘this is all the crap that you’re supposed to do, you know, whether or not you have cancer.’ Because it can be so easy to forget about all the other priorities. I mean having cancer is like a part-time job.” (PT)</p> <p>“I think [4R] forces the provider to sit down and talk through all this stuff, like slow way down and say like, ‘these are the things you’re doing next. These are the things we’re going to do at this time.’ I like the timeline [...], because it can, at least in my experience, it really felt like I have no idea if like I’m about to have cancer or like, if I wait a month to like find another doctor, like, is that okay? I don’t know, like, is this, you know, and so talking through the timeline, I love that. I think I love that for both the patient and the provider. I think that could really help a provider.” (PT)</p> <p>“Well, I think conceptually, [4R] is a good outline for what these patients should be focused on. And I think it’s probably helpful to me as well. Just sort of have it right in front of me about things I might not be thinking about during a given visit.” (CT)</p>

Abbreviations: 4R, Right Information and Right Care for the Right Patient at the Right Time; CT, clinical care team/stakeholder; PT, patient/caregiver.

primary care and oncology providers along the cancer care continuum, particularly across differing institutions, was largely characterized as inconsistent and inefficient. For patients, the lack of provider-provider communication between primary and oncology care teams meant more work for them amid an already emotionally and physically draining period of their lives. As one patient shared, "...when you get a diagnosis like that, all of a sudden there are more people involved in your care and no two facilities seem to handle that kind of thing exactly the same way. And I just felt like I spent a lot of time going, did I miss something? Am I doing this right? Was I supposed to do something else?" For patients who experienced limited communication and coordination between their primary care and cancer care providers, many felt that the burden of facilitating such communication fell to them, an experience commonly referred to as frustrating.

For clinical care team members, shortcomings in communication and coordination between providers were similarly frustrating. Clinical care team members spoke of both intra-organizational and interorganizational communication and coordination between providers in both primary care and oncologic care organizations. Struggles with intraorganization communication and coordination were attributed to internal silos between various components of care among large care organizations. As one member of a supportive oncology team described, "It's easy to end up kind of working in a silo where referrals get sent one way and get addressed in that area. And there really isn't much real collaboration."

A similar sentiment often arose when discussing interorganizational communication and coordination between primary care and oncology providers, particularly those out of network from one another. Clinical care team members identified limitations in electronic medical record infrastructure and electronic medical record incompatibility across differing organizations as barriers to effective communication and coordination between primary and oncology care sites. Clinical care team members from Howard Brown Health particularly mentioned the difficulties of gathering information from external oncology providers, which had to be delivered via fax hard copy when communication did occur. With no particular standard practice and limited infrastructure to facilitate efficient exchange between primary and oncology care providers in differing organizations, levels of communication were largely dependent on providers' effort. As one oncology nurse stated, "I mean really when it comes down to it, a lot of what falls through the cracks, it's just a simple lack of communication. I should say an effort to communicate." Although it was clear that many clinical care team members on both the primary care and oncology care sides of the cancer care continuum felt strongly about improving provider-provider communication, determining tangible strategies to do so appeared more challenging.

Referrals. Once engaged with oncology care, patient needs, along with referrals, shifted. Many patients spoke to the

important role of engagement with psychosocial and behavioral health resources and providers as they navigated the cancer care continuum. Participants agreed that psychosocial resources are particularly important for LGBTQ+ patients navigating cancer diagnosis. Despite this, engagement with, and integration of, psychosocial resources and behavioral health into the cancer care continuum via referral varied across those interviewed. Patient feedback regarding referrals to behavioral health resources largely fell into two categories: (1) they were referred to a behavioral health provider and found them to be very beneficial, or (2) they were not referred to a behavioral health provider and wished they had been.

4R as a care coordinating tool. Feedback regarding the 4R Care Sequence largely focused on the tool's potential to improve care coordination, including sequence of care events, and communication for both patients and providers along the cancer care continuum. As a physical (hard copy) form that could be brought to both primary care and oncology care visits, patients and clinical care team members reflected that the form's presence in clinic visits could provide an important overview of care. One clinical care team member noted, "It's easy to feel overwhelmed by all of the pieces [of care] because so many of them are not connected and very separate. So [the 4R Care Sequence] could be a great way of organizing it, and I think even help [patients] mentally organize what [their] needs are, and what they want to follow up on." The 4R form, which could be discussed during clinic visits, could further serve as a simple reminder to both patients and clinical care team members of ongoing patient care needs that might be forgotten or overlooked during short, and oftentimes busy, clinical visits. As one provider shared in reference to the 4R Care Sequence, "I think conceptually, this is a good outline for what these patients should be focused on. And I think it's probably helpful to me as well. Just [to] have it right in front of me—things I might not be thinking about during a given visit." As this provider reflected, the learning health system approach of the 4R form shows potential to identify shortcomings of care coordination at baseline and further help clinical care teams learn, in real time, how to improve clinical care operations and processes for LGBTQ+ patients. Clinical care team members in particular appreciated the inclusion of psychosocial and behavioral health components on the form, as they acknowledged these components of care are often missed during clinic visits.

Although interviewees appreciated the all-encompassing content of the 4R Care Sequence as a tool to help improve communication and care coordination, multiple patients and providers cautioned against placing too much information on the form and reintroducing the same problem of information overload initially encountered.

DISCUSSION

To our knowledge, this is one of the first studies to qualitatively investigate care coordination and patient-clinician

communication specifically for LGBTQ+ patients with cancer and LGBTQ+ cancer survivors. The findings from this study provide key insight for the development of interventions to improve collaboration within and between clinical teams to improve quality of care for and reduce health inequities among LGBTQ+ patients. Through the inclusion of not just patients, but also caregivers, clinical care team members, and representatives of community organizations, this study has created a robust picture of barriers and facilitators to care coordination and optimal care for LGBTQ+ patients with cancer and has provided evidence in support of the utility of a novel cancer care coordination model for LGBTQ+ patients.

Participants' reflections about the importance of identity- and gender-affirming care suggest that collaboration between providers to ensure their patients are provided a safe and informed environment, including receipt of appropriate resources and referrals to other identity- and gender-affirming providers, has the potential to greatly increase LGBTQ+ patients' quality of care. Given that discrimination and lack of LGBTQ+ competent providers are already barriers for many patients with cancer, clinical teams developing standards and guidelines across practices (which could include information related to gender- and identity-affirming provider referrals) could address this health inequity. The development of cross-practice, LGBTQ+ centered guidelines could also further work to combat provider-level implicit biases that prevent adequate utilization of, and patient benefit from, effective care coordination. In particular, the use of 4R Oncology Model care sequences with comprehensive care events may address some implicit biases that affect what care is discussed and offered to patients.⁴³ Part of this process may also include health care organizations adopting the practice of universal SOGI screening, so they may better identify and understand their patients' identities and ensure resources and referrals provided are appropriate. This may also include ensuring that clinical teams are aware of the local resources available to their patients and establish working relationships to improve the referral process. Additionally, participants' discussions about the importance of their support systems, often including chosen family, further suggest that clinical teams should make efforts to understand patients' main supports and include them as active members on their care teams. In 2021, the National LGBT Cancer Network published its OUT survey, which highlighted the experiences of LGBTQ+ patients throughout the cancer care continuum. In this national survey, 92% of surveyed participants responded that they felt satisfied with their overall cancer treatment experience.⁴⁴ With this, however, and in alignment with our own findings, surveyed participants noted difficulties finding LGBTQ+-specific cancer resources, spoke to the process of intentionally seeking out LGBTQ+ welcoming cancer care providers, and further asserted that social support networks and primary support persons were invaluable throughout care.⁴⁴

Although communication between patients and providers after a diagnosis of cancer was generally reported to be effective, the findings suggest the need for improvement in coordination between providers/clinical teams. Providers identified practice silos and inefficient information exchange as weaknesses in both interorganizational and intra-organizational collaboration. Better information sharing and communication between providers could improve clinical teams' understanding of a patient's progress and care needs. This may allow for prompt follow-up on medical needs and a decreased need for patients to bear the burden of communicating information on behalf of their providers. In many cases, incompatible electronic health record systems prevent the ease of health information sharing, which is where the 4R Care Sequence could be a useful bridge until system-wide interoperability solutions are implemented.

Finally, the direct involvement and inclusion of patients in their care via the 4R Oncology Model has the potential to increase patient agency and autonomy amid a care continuum that may make them feel otherwise. Use of the 4R model allows patients to be more aware of their cancer care coordination needs, to see gaps in their care, and to access vetted support organizations and resources. This allows patients to be fully informed and confidently voice concerns about how the care plan is being carried out if they wish. Although electronic patient portals are often available in the modern health information technological age, physical forms are a helpful resource for patients who do not have access to, or are not comfortable with, electronic portals.

Ultimately, to achieve improved cancer care coordination for LGBTQ+ patients, a multidisciplinary and multilevel approach will be necessary. LGBTQ+ patients with cancer deserve safe, affirming, and competent care, and the burden of both searching and advocating for such care should not fall on the shoulders of those most harmed by its absence; primary care sites, cancer centers, and the health care system as a whole must work to better provide effective, coordinated, LGBTQ+ competent care. Increased provider competencies and knowledge of appropriate LGBTQ+-relevant resources and organizations, universal SOGI data collection, and better communication between providers represent steps to achieving this goal.

Although this study aimed to produce a breadth of data regarding the personal experiences of various stakeholders in the cancer care continuum, four key limitations should be noted. First, interview participants represent a convenience sample recruited from Howard Brown Health and Northwestern Medicine patient, provider, and community organization networks. The sample of interviewed participants (N = 26) represents a relatively small sample size, reflecting a common difficulty with study recruitment during the COVID-19 pandemic.^{45,46} Second, although participants were diverse with respect to sexual and gender identities, the sample lacked racial/ethnic and economic diversity. Study participants were predominantly White, and most

interviewed patients were privately insured. With this, it is integral to explicitly recognize that the interviewed sample does not completely reflect the diversity of the LGBTQ+ community, especially when considering the way in which intersecting racial and socioeconomic identities overlap with those of gender and sexuality, and affect individual experience. More work must be done to understand the experiences of non-White, low-income, and underinsured/uninsured members of the LGBTQ+ community. Doing so would allow for better evaluation of 4R's effectiveness across the entire spectrum of the LGBTQ+ population. Third, although the qualitative research analysis reported here offers new insights into the care delivery experiences of LGBTQ+ cancer survivors, we acknowledge as a limitation that we did not delve into the experiences unique to specific groups within this heterogeneous population, such as gay, lesbian, bisexual, and transgender individuals. Finally, it is important to note that the majority of patients in this study received a portion of their care from HBH, an organization that has tailored its communication strategies and care practices to center the unique needs of LGBTQ+ patients. Identifying barriers to care in such a setting represents a crucial first step in dismantling barriers to LGBTQ+ health equity at CHCs and lays a foundation for future investigations at both CHCs and larger health care institutions that do not enshrine LGBTQ+ health equity in their mission. Thus, it will also be important to expand analysis to LGBTQ+ patients receiving care in other health care settings and organizations in future investigations to better understand barriers to communication and optimal care. Despite these limitations, this study produced valuable insight as we look to improve cancer and primary care coordination for LGBTQ+ patients moving forward.

In conclusion, in this report, we elucidate how a sample of LGBTQ+ patients, clinical care team members, caregivers,

and community organization representatives experienced, understood, and navigated coordination and communication throughout the cancer care continuum. Our results are consonant with some key findings from other studies focused on broader cancer patient populations. Notably, the inefficiency and nonstandardized nature of communication and coordination between primary and oncology care providers throughout the cancer care continuum have been repeatedly identified by both patients and providers in previous work.⁴⁷⁻⁴⁹ These shortcomings may potentially affect the disproportionality of LGBTQ+ communities and thus warrant further exploration.

The 4R Oncology model received favorable feedback with the potential to engage patients as members of care teams and bridge gaps in communication between clinical teams. The Learning Health System Model of the 4R Care Sequence facilitates timely refinement of 4R tools to respond to the identified needs of LGBTQ+ patients and their care teams. Although study interviews shed light on a number of realities of the cancer care continuum that appear in alignment with prior research on the subject, they also made clear a number of patient-, provider-, and system-level barriers and facilitators to integrated health care throughout the cancer care continuum for LGBTQ+ patients specifically. These findings thus have important implications for the tailoring and implementation of the 4R Oncology model and other interventions aimed at improving care coordination, patient experience, and outcomes in the cancer care continuum for LGBTQ+ patients. There is no single solution to optimizing team-based cancer care, but 4R shows potential to assist multidisciplinary and cross-institutional care teams in providing coordinated, integrated, equity-centered, and complete care to LGBTQ+ patients.

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A Learning Health System Approach to Cancer Survivorship Care Among LGBTQ+ Communities

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