

# Improving virtual cancer care for older Black adults: A qualitative study

Paul Wankah, Shivani Chandra, Aisha Lofters, Nebila Mohamednur, Beverley Osei, Tutsirai Makuwaza, Ambreen Sayani

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### Improving virtual cancer care for older Black adults: A qualitative study

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#### Abstract

**Background:** Health systems are rapidly promoting virtual cancer care models to improve cancer care of their populations. However, virtual cancer care can exacerbate inequities in cancer care for communities experiencing social disadvantaged. Older Black cancer patients face unique challenges to accessing and utilizing virtual cancer care.

**Objective:** This study focused on understanding the virtual cancer care experience of older Black patients, their caregivers and healthcare providers to identify strategies that can better support patient-centered virtual cancer care.

**Methods:** A theory-informed thematic analysis was conducted using data collected from six focus groups (N = 55 participants) conducted across ten Canadian provinces. Data coding and thematic analysis was informed by the Patient Centered Care model and the synergies of oppression conceptual lens.

**Results:** Five overarching themes describe the experience of older Black patients, caregivers and health care providers in accessing and utilizing virtual cancer care: i) heightened inequities at the intersection of multiple systems of oppression; ii) shifting caregivers' dynamics; iii) autonomy of choice and choosing based on the purpose of care; iv) digital accessibility and v) effective digital communication. We identify eight barriers and six facilitators to optimal virtual cancer for older Black adults. Barriers include limited digital literacy, linguistic barriers in traditional African/Caribbean languages, and culturally mediated views of patients; and facilitators include community-based cancer support groups, caregivers support and key features of digital technologies.

Conclusions: A multipronged approach that simultaneously focuses on addressing barriers and leveraging community strengths can improve access and utilization of virtual cancer care. A redesign of virtual cancer care programs, tailored to the needs of most structurally marginalized groups like older Black adults can enhance the virtual care experience for all population groups. Public policies and organizational practices that address issues like availability of internet in remote areas, resources to support linguistic barriers or culturally sensitive training are important in responding to the complexity of access to virtual cancer care. These findings have implications for other structurally marginalized and underserved communities that have suboptimal access and utilization of virtual care. Clinical Trial: N/A

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# **Original Manuscript**

#### Title: Improving virtual cancer care for older Black adults: A qualitative study

#### **Introduction:**

Virtual care is defined as "the secure use of information and communication technologies in support of health and health-related fields, including health care services, health surveillance, health literature, and health education, knowledge, and research" [1]. Used in complement with or in lieu of in-person encounters, virtual care encompasses a wide array of modalities including phone calls, video conferencing, remote monitoring, asynchronous messaging (e.g., e-mail, texting) and the use of a patient portal [1]. Virtual cancer care has been shown to be effective for pretreatment discussions, the monitoring of adverse events, for counselling purposes, and for long-term cancer care follow-up [2]. However, there is a growing body of evidence which demonstrates inequitable access of virtual care services – resulting in a widening health gap between population groups that are able to utilize virtual care versus those that cannot. Reasons for this include an inability to afford the necessary technology, lack of language accessibility within certain applications, lack of infrastructure to support digital connectivity in rural areas, lack of cultural relevance of care provision, and lower levels of comfort in using certain technologies [3–6].

Structurally underserved [7] and marginalized population subgroups, such as older Black adults experience barriers specific to their identity such as physical, cognitive, and/or sensory limitations/concerns [8]; lack of social/peer support to help with use of technology [9]; and preference for in-person visits due to limited trust in technology and concerns about privacy [10]. When services are available, acceptability of care [11] is determined by a lack of cultural tailoring of language used in service/technology [12], varying views/beliefs for disease management [13] and existing historic and societal barriers such as general distrust of health care providers [14].

While other countries report that cancer disproportionately affects Black people [15], the lack of comprehensive race-based data collection in Canada means that the extent of the care gap affecting Black Canadians is unknown. However, a recent study that used census data to explore patterns of mortality inequalities of Black adults in Canada indicates that Black men had an increased risk of dying from prostate cancer (Hazard Ratio: 1.33) than their White counterparts, and Black women were at an increased risk of dying from stomach cancer (Hazard Ratio: 1.76), corpus uteri cancer (Hazard Ratio: 1.78), and lymphomas and multiple myelomas (Hazard Ratio: 1.26) than their White counterparts [16]. With limited race-based data collection, it is also unclear how race and racism affect virtual cancer care use in Canada. It is essential that virtual cancer care is delivered in a manner that meets the needs of all communities and does not exacerbate inequities between the most privileged and the most underserved communities. Knowledge generated in partnership with these communities is essential to developing health care policy and planning that focuses on enhancing equity in access to and quality of virtual care. Hence, the purpose of this study was to better understand the virtual cancer care experiences of older Black cancer patients, their caregivers, and health care providers. Through this understanding, we sought to identify strategies that can support the delivery of better patient-centred virtual cancer care.

#### **Methods**

#### **Study Design and Theoretical Approach**

We used theoretical thematic analysis [17] as a methodology in order to conceptualize, collect, organize and interpret data using the synergies of oppression lens [18] and guided by the Patient-Centred Care model [19]. The synergies of oppression lens [18] is an approach that brings to the fore the intersection of multiple systems of oppression that shape the lived experience of older Black cancer patients as they navigate the health system. Characteristics such as race, age, level of disability, sex and gender, and income levels of individual and social groups are powerful indicators of their access to material and social resources that are necessary to achieve health and wellness. These characteristics (or multiple oppressions) operate in complex synergistic patterns that lead to poor health and have been used previously to unpack and understand inequities in cancer care [20-24]. In this study, we have used the synergies of oppression analytical lens to theorize a combination of oppressions impacting the virtual care experiences of older Black cancer patients. We were also guided by the seven dimensions of Patient-Centred Care [19] model that outlines the essential components of a patient-responsive health care as i) aligning the health system's vision, mission, values and quality improvement drivers to patient-centred goals, ii) providing collaborative, coordinated and accessible care at the right time and the right place, iii) providing care that considers physical comfort and emotional wellbeing, iv) respecting patient and family preferences, values, and cultural traditions in the organization and delivery of care, v) integrating family and patients in care teams, and having them fully partake in decision-making at the clinical and system level, vi) encouraging and facilitating the presence of family members in care settings and vii) supporting informed decision-making by patients and their family by providing complete information in a timely manner. Accordingly, our study questions were:

- 1. What is the experience of older Black patients who have used virtual cancer care?
- 2. How can we improve the virtual cancer care experience of older Black cancer patients?

We hypothesize that strategies and interventions which will improve the virtual cancer care experience of populations that are experiencing the most structural marginalization, will improve the virtual cancer care experience across all population groups in alignment with Bell Hooks concept of "centering the margins" [25,26].

#### Participant recruitment and setting

This study was carried out between May 2022 and March 2023. Three groups of study participants were targeted by this study;

- i) *patients*: comprised of older Black patients, 55 years old and above, who had been diagnosed with any form of cancer, including those no longer in active treatment, and had used virtual cancer care services across the 10 Canadian provinces;
- ii) *caregivers*: comprised of any individual who provided informal support in activities of daily living to older Black cancer patients this included family or paid caregivers; and
- iii) *providers* : comprised of health care professionals who regularly delivered clinical care to older Black cancer patients.

Sampling was carried out through a non-probabilistic convenience approach. This sampling strategy allowed us to cover various contexts (urban, rural, remote) and diverse informants who could provide rich data on their experiences in receiving and delivering virtual cancer care to older Black patients. The recruitment of potential study participants was supported by the Canadian Cancer Society (CCS), which is the largest cancer charity in Canada. The CCS posted invitations to participate in the

study using their database of cancer patients, caregivers and health care professionals. Those who were interested to participate in the study contacted the project coordinator by e-mail. We sent detailed information letters on the study to potential participants. Six groups of participants were created, considering time zones and provincial linguistic diversity: i) patients and caregivers in the Eastern provinces (Newfoundland and Labrador, Nova Scotia, Prince Edward Island); ii) patients and caregivers in Central/Prairies provinces (Ontario and Manitoba); iii) patients and caregivers in Western/Prairies provinces (Saskatchewan, Alberta and British Columbia); iv) patients and caregivers in Francophone/Bilingual provinces (Quebec and New Brunswick); v) health care providers in eight Canadian provinces; and vi) health care providers in Francophone/bilingual provinces (Quebec and New Brunswick) see table 1. The final study comprised 55 participants across the 6 groups (table 1).

Table 1: Number of participants in the focus groups

Focus group		Number of
		participants
Patients with lived experience and	Eastern Provinces (NF, NB, NS,	12
Caregivers	PEI)	
	Central & Prairie Provinces (ON,	10
	MB)	
	Western & Prairie Provinces (BC,	10
	AB, SK)	
	Francophone/bilingual provinces	8
	(QC, NB)	
Health care providers	English-speaking provinces	10
	Francophone/bilingual provinces	5
	Total	55

#### Data collection

Data was collected through six focus group interviews with the aforementioned groups of participants (Table 1). Focus group interviews were led by two Black peer researchers (PW, TM). This was an intentional and important strategy to reduce mistrust of the research process and to increase study participation by leveraging existing relationships between Black communities in Canada. During the focus group interviews we used two distinct interview guides — a patient/caregiver interview guide (supplementary file 1) and a health care provider interview guide (supplementary file 2) — to guide data collection. Both interview guides were developed from the research objectives and targeted literature review. Questions in the interview guides were structured to unpack issues of access and utilization of virtual cancer care and included probes relating to the roles of various actors in the usage of virtual care, preference for various virtual care modalities, frequency of virtual care use, experiences and challenges during the usage of virtual care. All focus groups were carried out online using the Zoom video teleconferencing software and sessions were recorded with permission. The audio files of the recordings were transcribed verbatim for data analysis.

Following the focus group interview, a socio-demographic survey was sent to each focus group participant to better understand the diversity of age, income and other socio-demographic characteristics that were present in the focus groups. Participation in the socio-demographic survey

was optional. Ethics approval was obtained from Women's College Hospital Research Ethics Board.

#### **Data analysis**

Data analysis was facilitated by the Nvivo 11 qualitative data analysis software. Qualitative data analysis was carried out according to the six steps of thematic analysis of Braun and Clarke [17]. Transcripts were read and re-read by all authors before coding began. A codebook was developed based on the key elements of the Patient-Centred Care model [19]. Subsequently line-by-line coding was applied to the transcripts (by PW and AS). Additional codes were developed and modified through group discussion until all lines of the transcripts had been coded. Excerpts of data from focus group interviews were attributed to various codes, a detailed description of each code was done to better understand the lived/ living experiences of participants. Finally, we synthesized the data into themes and subthemes that illuminated the experiences of patients, caregivers and health care providers on virtual cancer care for older Black adults. We analyzed the results of the sociodemographic survey using descriptive measures.

#### **Findings**

#### Socio-demographic results

Of the 55 socio-demographic surveys that were sent to research participants, 24 were completed by patients and/or caregivers (table 2). No health care providers completed the survey.

About two thirds of patients and caregivers who participated in the focus group identified as male, and the same proportion of participants were between 50-64 years old. Most participants (20/21) had college-level education or higher. More than half of the participants had part-time jobs. There was great diversity in the household income level of participants, with more than half of them earning less than \$60,000 per year.

Table 2: Socio-demographic profile of participants

Gender	Number of
	participants*
Male	16
Female	7
Age	
50-64	15
65+	7
Highest level of education	
Primary or middle school	1
Undergraduate degree	7
College	6
diploma/degree/certificate	
Master's degree	7
Employment	
Full-time	6
Part-time	11
Self-employed	1
Casual	1
Household income	
\$ 0- 29,999	6
\$ 30,000 – 59,999	4
\$ 60,000 – 89,999	3
\$ 90,000 – 119,999	4
\$ 120,000 - 150,000	2

<sup>\*</sup>Numbers don't always add up to 24 because of incomplete surveys/missing data

#### Thematic results

The experiences of patients, caregivers, and health care providers on the use of virtual cancer care for older Black adults were related to these five main areas, 1) heightened inequities at the intersection of multiple systems of oppression, 2) shifting caregiver dynamics, 3) autonomy of choice and choosing based on the purpose of care, 4) digital accessibility, and 5) effective digital communication.

#### Heightened inequities at the intersection of multiple systems of oppression

Our findings reflected that older Black cancer patients are not a homogenous group with respect to their lived experience of virtual care. They are a heterogenous group comprised of individuals with unique needs and lived experiences. Additionally, individuals within this group will have experienced systems of oppressions to various degrees, which has shaped the way they experienced virtual cancer care. Our data shows four main challenges that were experienced by older Black patients:

i) *Multimorbidity* seemed to be the most salient challenge that influenced the capacity of older Black cancer patients to participate in virtual encounters. Across the six focus groups, study respondents often talked about two main features of multimorbidity that limited the capacity of patients to effectively engage in virtual encounters. First, the severity of the patient's cancer marked by clinical symptoms such as intense chronic pain, loss of autonomy in activities of daily living and persistent mental fatigue meant that older Black patients were not always capable to fully participate in virtual encounters. Second, another aspect of multimorbidity was related to the adverse effects of chemotherapy, as explained by a caregiver:

"I think sometimes we have to consider the patient's state of mind, maybe how long the person just finished taking a medication; the amount of time before you could engage them in a virtual meeting [...] you have to look at the possibility of the patient being stable before you could engage into any important communication so that you might not end up getting misinformed by the patient just because of the reactions of medications." (FG 1 - Caregiver)

Several respondents pointed out that chemotherapy is exhausting for most cancer patients. Older Black patients lost appetite, had nausea and vomiting as well as fatigue after rounds of chemotherapy. These patients could not effectively participate in virtual meetings without assistance.

ii) The *geographic location* of patients emerged as another issue of concern for virtual cancer care as explained by a patient:

"And I will say maybe most times people in the rural areas tend not to have a good stable communication network system" (FG 4 – Patient)

Participants highlighted issues related to internet connection in rural and remote areas. Internet was often unreliable – they may spend days without any connections so they cannot join the virtual meeting; unstable – they may have an intermittent internet connection, so they are often disconnected from the virtual meeting; or low bandwidth – the poor quality of internet meant the connection is very slow.

iii) *Socially isolated* older Black patients were reported as having difficulties in accessing virtual care. One respondent talked about a community-based initiative called the African Cancer Support Group that was launched to support socially isolated individuals of African and Caribbean descent in Alberta.

"I say that because we have these groups called the African Cancer Support Group to help the friends of Africans or Caribbean and Black Canadians going through cancer. [...] We're able to provide some patients with computers" (FG 4- Caregiver)

This support group identified lack of access to digital technologies such as computers, smart phones, and tablets as an obstacle to virtual care for socially isolated Black patients. One way in which they supported this disadvantaged group was by providing computers to enhance access to virtual care.

iv) *Linguistic barriers* emerged as a unique challenge to virtual care as explained by a health care provider:

"Language barrier is kind of something that is digging deep to the Blacks because we have different kinds of languages" (FG 5 – Health care provider)

Our study participants pointed out that some older Black cancer patients were not fluent in English or French, the official languages of Canada. Health care providers were also concerned that Black seniors seemed to be more proficient in traditional African/Caribbean languages such as Swahili or Patois. These languages are not easily understood by health care professionals, and it was difficult to find trained interpreters that could facilitate communication with these patients.

#### **Shifting caregiver dynamics**

Across the six focus groups, there was increasing recognition of the central role of caregivers in enabling and supporting virtual cancer care for older Black patients. Respondents pointed out four main aspects of the shifting roles of caregivers as a dynamic process:

i) Caregivers were critical in supporting patients with limited digital literacy before, during and after the virtual encounter:

"But one of the things that was a concern for me was because my mom is elderly and she's not really tech savvy, so I had to take charge of all portals and mail and all of that," (FG 2 - Caregiver)

- ii) Caregivers were more involved in direct caregiving to their patient a role that was traditionally reserved for health care providers. While family caregivers with no prior experience or health care training seemed to be less comfortable in providing direct care, paid caregivers seemed to be more comfortable in providing direct care.
- iii) As caregivers were more involved in supporting virtual care and providing direct care to Black seniors, there were privacy concerns related to the roles of caregivers. Specifically, some autonomous patients preferred privacy during their virtual meetings:

"Like I said earlier, he has prostate cancer, and I think most times there are moments he wants to say things that are personal. So, at the moment, I like to understand his privacy and I'll give him that privacy" (FG 4 - Caregiver)

Other patients with cognitive disorders who needed support from caregivers were not concerned about privacy:

"So, I think in terms of privacy, because already my patient has a little bit of memory loss, so I think without me being there, I think most things would be left untold" (FG 4 - Caregiver) And family caregivers like a spouse supporting the partner in virtual care did not consider privacy an issue:

"I'm not worried about privacy, it's my husband. If the patient is the wife, what kind of privacy? And mostly when you are filling the form, you put all the information they're on the form, so they already know everything about you." (FG 4 - Caregiver)

iv) Some older Black patients expressed anxieties about their children who became caregivers. Specifically, the emerging role of caregivers gave rise to a shift in power or influence where caregivers are more involved in decision-making. Some older Black patients were confronted with their children having more influence in their health care – a role that children do not traditionally

hold in these cultures and societies.

#### Autonomy of choice and choosing based on the purpose of care

Focus group participants often positioned virtual care dualities and in-person care as alternative and complementary means of delivering care for older Black cancer patients.

i) By using virtual care, patients particularly appreciated the convenience and comfort of receiving care in their homes as explained by a patient:

"You can stay at the comfort of your home. And when you have a virtual conversation with your specialist, you feel this level of comfort. And you can tell your specialist how you're actually feeling." (FG 4- Patient)

Three other benefits of virtual care for patients that emerged from our data included easy access to their specialist, feeling safe by not being exposed to the general population during the COVID-19 pandemic, and older Black adults felt more empowered and confident to participate in their care.

- ii) Caregivers and health care providers often talked about and greatly appreciated the flexibility of virtual care in adjusting their work schedules.
- iii) Despite these benefits, our respondents recognized that virtual care was not always realistic or possible in the continuum of cancer care. They explicitly pointed out areas of their cancer care where virtual care was impractical. One patient pointed out the need for a physician examination:

"I'll say that I prefer in person because while I'm communicating in person, there are some physical examinations and some things I may want to explain myself, which I wouldn't be able to do virtually so I prefer in person." (FG 1 - Patient)

Acute conditions like a fever that needed urgent and emergency care, cancer biopsies, treatment modalities like radiotherapy, and sample collection for laboratory examinations were explicitly mentioned by focus group participants as other situations that they would rather have in-person care.

iv) Some focus group members argued for more hybrid models of care delivery that integrated virtual care and other care modalities like home care and ambulatory care.

#### **Digital accessibility**

Study participants recognized that an important aspect of virtual care meant that they had to frequently use information and communication technologies for their routine care needs. While most of our study participants were relatively comfortable with technology, certain areas of concern emerged from the interviews.

Digital literacy was identified as a problem for all participant groups - patients, caregivers and health care providers. Older Black adults with limited digital literacy had difficulties in understanding and using computers, tablets or applications. They needed support from caregivers and health care professionals. Interestingly, some caregivers and health care professionals also faced digital literacy issues as explained by a health care provider:

"Yes, actually, it was more time intensive, and it was more stressful because I wouldn't say I'm that good at tech myself. " (FG 6 - Health care provider)

The limited capacities of participants to use digital technologies could be frustrating in preparing and operating virtual encounters.

Some caregivers and health care providers mentioned that they had to invest time and efforts to improve their digital literacy skills and competencies in order to be ready to effectively support their patients:

"During the pandemic, I had to learn a lot of technology skills and at the time I was involved with a virtual meeting with my patient, helping him set up virtual care with his GP and with

his oncologist and every kind of health professionals involved with my patient." (FG 2 - Caregiver)

Certain health care organizations offered training resources to help health care providers to improve tech skills.

Finally, we noticed that older Black patients often said that they could not easily build their digital literacy skills due to their age and the burden of cancer on their daily lives. This means that the older Black patients were more reliant on their caregivers for their virtual care needs. In this situation, patients seemed to value or prefer caregivers that are compassionate and patient in the way they provided support and assistance during virtual encounters:

"I think for me, say one of the important things that I benefited from my caregiver, she's very patient with me. That is one thing I benefit from her. Because I think at the time, it took me almost a month to be able to navigate using virtual care. She was there for me, and her patience was something that ... I mean, I can't comprehend on the time, because she took the time to put me through, stage by stage, for me to understand what I was doing, and how to do it." (FG 3 - Patient)

#### **Effective digital communication**

As focus group participants frequently talked about the importance of digital technologies as a medium for good communication and information exchange with their health care team, there were some concerns about confidentiality and privacy. Specifically, we noticed a cultural aspect of privacy where older Black patients were reluctant to share their health information with their children as explained by a patient:

"Yeah, when I had my kids around there were times when I was uncomfortable because there were some things I couldn't answer out loud, so I just did mute it when the question was asked and sometimes I would just tell my doctor, not now (inaudible) when we have a physical appointment or something, or maybe later when it's just me and my wife. If it's just my wife, I can say anything I want to say, but when my kids are around I have to limit what I say because I don't want them having this idea that something terrible is going to happen to dad and all that." (FG 2 - Patient)

These older Black patients seemed to be less concerned about sharing information with their spouses. Our focus group participants also identified other areas where virtual technologies could enhance communication such as i) having transcripts of conversations after the virtual encounter, ii) live translations for people that speak different languages, or iii) including or using features of technology to improve care for people with visual or hearing impairments:

"And when it comes to hearing impairment, I think there's something you use in your ear that could help improve your hearing aid. So, when you're looking at things, you have to look at these tools equally so that you don't know whether you're dealing with a patient that has a hearing problem or an eye problem" (FG 2 – Caregiver)

A summary of barriers and facilitators to virtual cancer care based on interview findings is shown in Table 3.

Table 3: Barriers and facilitators to virtual cancer care for older Black adults.

Barriers to virtual cancer care	Facilitators to virtual cancer care
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Limited engagement in virtual encounters of patients fatigued by cancer and chemo/radiotherapy	Community-based cancer support groups provided computers to socially isolated older Black patients
Difficulties to connect to virtual encounters due to limited and unstable internet connections in rural and remote areas	Caregivers supported patients with limited digital literacy before, during and after the virtual encounter.
Socially isolated older Black patients had limited access to digital technologies	Patients felt comfortable receiving virtual cancer care in their homes
Difficult communication between patients and providers during virtual encounters due to linguistic barriers in traditional African/Caribbean languages	Virtual cancer care offered great flexibility to the work schedules of caregivers and health care providers
Privacy concerns when caregivers supported competent patients during virtual encounters	Building digital literacy skills of caregivers and providers to provide better support to older Black patients.
Difficulties in using virtual care technologies due to limited digital literacy of patients, caregivers and providers	Key features of digital technologies such as visual and hearing aids or the capacity to have transcripts of virtual meetings motivated actors to uptake virtual cancer care
Culturally mediated of views of children supporting their parents for virtual cancer care  Virtual care was impractical in emergency situations	

#### **Discussion**

Inequities in cancer outcomes can be linked to higher cancer risk, delayed diagnosis and unequal opportunities to access timely treatment. This is more significant for certain population groups that experience marginalized social conditions that are shaped by stigma, discrimination and intergenerational trauma [15,27]. Inequities in cancer care can be further exacerbated at the intersection of social identities with other marginalizing conditions such as unequal access to the social determinants of health, resulting in health inequities that are structured and reinforced by the health care system [22]. One example of this can be the rapid shift of cancer care services from traditional in-person care towards virtual cancer care models that arose in response to social distancing measures during the COVID-19 pandemic [28,29]. The implications of this shift – and the resulting impact in terms of access and optimal virtual cancer care for populations that experience marginalizing social conditions is still unknown. In our study we sought to unpack these issues so that we can inform the redesign of virtual cancer care to meet the needs and priorities of underserved communities – thereby enabling better virtual cancer care for everyone.

Specifically, we identified eight barriers to an optimal virtual cancer encounter such as linguistic barriers and limited digital literacy, and six facilitators that can enhance the virtual cancer care experiences of older Black adults such as community-based cancer support groups and flexible work schedules (table 3). These findings concur with previous studies on the barriers and facilitators of virtual cancer care [2,9,30]. Efforts to improve virtual cancer care will require a multipronged approach that targets these specific barriers to virtual care while creating system-wide policies that encourage these facilitators and influence the distribution of social determinants of health. For

instance, policy interventions may be required to improve the stability of internet connections in rural and remote areas, while interpretation resource guides may help health care providers to know what translation/interpretation resources are available to them at the local/provincial and national level to overcome linguistic barriers. While these multipronged interventions will improve the virtual cancer care experience for older Black adults, they are also equity-promoting for other underserved communities and can enhance care for all.

Some of the findings of our study were specific to the social identity of our participants. First, our findings revealed an increasing recognition of the critical role of caregivers in supporting older Black adults in accessing and using virtual cancer care. Older Black adults who are fatigued due to cancer multimorbidity, who had limited digital literacy, or who had cognitive disorders due to cancer relied on the support of caregivers before, during and after virtual encounters. However, we also noticed that autonomous patients had privacy concerns when supported by caregivers for their virtual caner care needs. This implies that there is urgent need for guidance at the policy and organizational level on the roles and scope of practice of caregivers in supporting virtual cancer care that is tailored to the unique needs of cancer patients.

Second, previous studies suggest that the cultural background of racialized patients influence their views on symptoms, diagnosis and treatments that may hinder access to cancer care [27]. Our findings unravelled culturally mediated views of older Black cancer patients who were confronted with their children having more influence in their health care during virtual encounters and who were reluctant to share their health information with their children. These culturally mediated dynamics between older Black cancer patients and their children have to be taken into consideration during virtual cancer care. Framing virtual cancer care in the context of a person's cultural understanding of health requires the health care provider to have an awareness of the community that they serve [27]. This implies that efforts to develop culturally sensitive guides to virtual care may be an important step to supporting health care providers to providing culturally appropriate virtual cancer care to older Black patients.

#### **Strengths and Limitations**

We used the synergies of oppression framework [18] to conceptualize the virtual cancer care experiences of older Black patients, caregivers and health care providers within their social context. This theoretical thematic analysis approach allowed us to illuminate how the ability to access virtual cancer care of older Black patients is shaped by intersecting oppressions that display themselves as structured social disadvantage. A key strength of the theoretical thematic analysis approach is the ability to produce evidence that is relevant to developing policies, organizational and clinical practices that respond to the needs of patients, caregivers and health care providers.

We were limited by the methodological approach of studying virtual care through virtual methods. Given that the study population spanned ten Canadian provinces, all the focus group interviews were carried out through a virtual communication platform. This might have caused a selection bias where potential study participants with limited access to virtual technologies could not participate in our study. However, the purpose of our study was to understand and enhance virtual cancer care experiences in populations who had utilized virtual care. Further community-engaged research is needed to understand which sub-populations of older Black adults can and do utilize virtual cancer care versus the lived/living experiences of those that do not or cannot utilize virtual cancer care.

#### Conclusion

Older Black patients face multiple barriers to accessing and using virtual cancer care. A multipronged approach that focuses on addressing barriers, encouraging facilitators, and creating culturally sensitive guides to virtual care can form the basis of health system efforts to improve access to virtual cancer care. A redesign of virtual cancer care programs, tailored to the needs of marginalized social groups like older Black patients can enhance the virtual care experience for all population groups. Public policies and organizational practices that address issues like availability of internet in remote areas, resources to support linguistic barriers or culturally sensitive training are important in responding to the complexity of access to virtual cancer care.

#### Acknowledgements

Not applicable

#### **Authors' contributions**

AS, AL and SC designed the study; PW and SC recruited study participants; PW and TM collected data; PW, AS, SC, NM, and BO analyzed and interpreted the data; all the authors contributed in writing the manuscript.

#### **Funding statement**

This study has been commissioned by the Canadian Cancer Society, through funding they received from Merck Inc. The Canadian Cancer Society assisted in the recruitment of potential study participants.

#### **Data availability**

Data supporting the findings of this study are available upon request from the corresponding author.

#### **Declarations**

#### Ethics approval and consent to participate

All experiments were performed in accordance with the guiding principles of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2 (TCPS 2). All study participants were informed about the purpose of this study and signed informed consent forms before participating in focus groups. Research Ethics Board approval was obtained from Women's College Hospital.

#### **Consent for publication**

Not applicable

#### **Conflicts of interests**

PW is a recipient of the Provost's Postdoctoral Fellowship from the University of Toronto.

AS is a recipient of the Transition to Leadership Stream Award in Patient-Oriented Research from the Canadian Institutes for Health Research and is a Health Equity Expert Advisor to the Canadian Partnership Against Cancer (CPAC).

AL is supported as Clinician Scientist by the Department of Family Medicine at the University of Toronto and as Chair of Implementation Science at the Peter Gilgan Centre for Women's Cancers at

Women's College Hospital in partnership with the Canadian Cancer Society. All the other authors do not declare any competing interests.

#### References

- 1. Demaerschalk BM, Hollander JE, Krupinski E, Scott J, Albert D, Bobokalonova Z, et al. Quality Frameworks for Virtual Care: Expert Panel Recommendations. Mayo Clin. Proc. Innov. Qual. Outcomes 2023;7:31–44. https://doi.org/10.1016/j.mayocpiqo.2022.12.001
- 2. Singh S, Fletcher GG, Yao X, Sussman J. Virtual care in patients with cancer: a systematic review. Curr. Oncol. 2021;28:3488–506.
- 3. Veinot TC, Mitchell H, Ancker JS. Good intentions are not enough: how informatics interventions can worsen inequality. J. Am. Med. Inform. Assoc. 2018;25:1080–8.
- 4. Weiss D, Rydland HT, Øversveen E, Jensen MR, Solhaug S, Krokstad S. Innovative technologies and social inequalities in health: A scoping review of the literature. PloS One 2018;13:1–20. https://doi.org/10.1371/journal.pone.0195447
- 5. Latulippe K, Hamel C, Giroux D. Social health inequalities and eHealth: A literature review with qualitative synthesis of theoretical and empirical studies. J. Med. Internet Res. 2017;19:1–14. https://doi.org/10.2196/jmir.6731
- 6. Smith B, Magnani JW. New technologies, new disparities: The intersection of electronic health and digital health literacy. Int. J. Cardiol. 2019;292:280–2. https://doi.org/10.1016/j.ijcard.2019.05.066
- 7. Ho K, Adams O, Sayani A, Cheema G. Defining "Essential Digital Health for the Underserved." Healthc. Pap. 2024;21:5–14. https://doi.org/10.12927/hcpap.2024.27276
- 8. Batsis JA, DiMilia PR, Seo LM, Fortuna KL, Kennedy MA, Blunt HB, et al. Effectiveness of Ambulatory Telemedicine Care in Older Adults: A Systematic Review. J. Am. Geriatr. Soc. JAGS 2019;67:1737–49. https://doi.org/10.1111/jgs.15959
- 9. Arsenijevic J, Tummers L, Bosma N. Adherence to electronic health tools among vulnerable groups: Systematic literature review and meta-analysis. J. Med. Internet Res. 2020;22:1–18. https://doi.org/10.2196/11613
- 10. Fang M, Siden E, Korol A, Demestihas M, Sixsmith J, Sixsmith A. A scoping review exploration of the intended and unintended consequences of eHeath on older people: A health equity impact assessment. Hum. Technol. 2018;14:297–323. https://doi.org/DOI: 10.17011/ht/urn.201811224835
- 11. Sayani A, Ali MA, Dey P, Corrado AM, Ziegler C, Nicholson E, et al. Interventions Designed to Increase the Uptake of Lung Cancer Screening: An Equity-Oriented Scoping Review. JTO Clin. Res. Rep. [Internet] 2023;4. Available from: http://dx.doi.org/10.1016/j.jtocrr.2023.100469. https://doi.org/10.1016/j.jtocrr.2023.100469
- 12. Bennett GG, Steinberg DM, Stoute C, Lanpher M, Lane I, Askew S, et al. Electronic health (eHealth) interventions for weight management among racial/ethnic minority adults: a systematic review. Obes. Rev. 2014;15:146–58. https://doi.org/10.1111/obr.12218

13. Jang M, Johnson CM, D'Eramo-Melkus G, Vorderstrasse AA. Participation of Racial and Ethnic Minorities in Technology-Based Interventions to Self-Manage Type 2 Diabetes: A Scoping Review. J. Transcult. Nurs. 2018;29:292–307. https://doi.org/10.1177/1043659617723074

- 14. Ashfaq A, Esmaili S, Najjar M, Batool F, Mukatash T, Al-Ani HA, et al. Utilization of mobile mental health services among syrian refugees and other vulnerable arab populations—a systematic review. Int. J. Environ. Res. Public. Health 2020;17:1–15. https://doi.org/10.3390/ijerph17041295
- 15. Giaquinto AN, Miller KD, Tossas KY, Winn RA, Jemal A, Siegel RL. Cancer statistics for African American/Black People 2022. CA. Cancer J. Clin. 2022;72:202–29. https://doi.org/10.3322/caac.21718
- 16. Tjepkema M, Christidis T, Olaniyan T, Hwee J. Mortality inequalities of Black adults in Canada. Health Rep. 2023;34:3–16. https://doi.org/10.25318/82-003-x202300200001-eng
- 17. Braun V, Clarke V. Using thematic analysis in psychology. Qual. Res. Psychol. 2006;3:77–101. https://doi.org/10.1191/1478088706qp063oa
- 18. McGibbon E, McPherson C. Applying Intersectionality & Complexity Theory to Address the Social Determinants of Women's Health. 2011 May [cited 2023 1]; Available from: https://tspace.library.utoronto.ca/handle/1807/27217
- 19. Gerteis M, Edgman-Levitan S, Daley D, Delbanco T. Through the patient's eyes: understanding and promoting patient-centred care. 1st ed. San Francisco: Jossey-Bass; 1993.
- 20. Sayani A. Socially based inequities in breast cancer care: intersections of the social determinants of health and the cancer care continuum. Crit. Stud. Int. Interdiscip. J. 2017;13:24–36.
- 21. Sayani A. Inequities in genetic testing for hereditary breast cancer: implications for public health practice. BMC Immunol. 2019;10:35–9. https://doi.org/10.1007/s12687-018-0370-8
- 22. Sayani A. Health equity in national cancer control plans: An analysis of the ontario cancer plan. Int. J. Health Policy Manag. 2019;8:550–6. https://doi.org/10.15171/ijhpm.2019.40
- 23. Sayani A, Dilney J, Kuhnke JL, McNeil T. "My Cancer Is Worth Only Fifteen Weeks"? A Critical Analysis of the Lived Experiences of Financial Toxicity and Cancer in Canada. Int. J. Health Policy Manag. 2022;11:1814–22. https://doi.org/10.34172/IJHPM.2021.83
- 24. Sayani A, Vahabi M, O'Brien MA, Liu G, Hwang SW, Selby P, et al. Perspectives of family physicians towards access to lung cancer screening for individuals living with low income a qualitative study. BMC Fam. Pract. 2021;22:10–10. https://doi.org/10.1186/s12875-020-01354-
- 25. Hooks B. Feminist theory: from margin to center. 3rd ed. New York; Routledge; 2015. https://doi.org/10.4324/9781315743172
- 26. Sayani A, Cordeaux E, Wu K, Awil F, Garcia V, Hinds R, et al. Using the Power Wheel as a transformative tool to promote equity through spaces and places of patient engagement. BMJ

- Open 2024;14:1–8. https://doi.org/10.1136/bmjopen-2023-074277
- 27. Ezeife DA, Padmore G, Vaska M, Truong TH. Ensuring equitable access to cancer care for Black patients in Canada. Can. Med. Assoc. J. CMAJ 2022;194:E1416–9. https://doi.org/10.1503/cmaj.212076
- 28. Berlin A, Lovas M, Truong T, Melwani S, Liu J, Liu ZA, et al. Implementation and Outcomes of Virtual Care Across a Tertiary Cancer Center During COVID-19. JAMA Oncol. 2021;7:597–602. https://doi.org/10.1001/jamaoncol.2020.6982
- 29. Watson L, Qi S, Delure A, Link C, Photitai E, Chmielewski L, et al. Virtual cancer care during the COVID-19 pandemic in Alberta: Evidence from a mixed methods evaluation and key learnings. JCO Oncol. Pract. 2021;17:1354–61. https://doi.org/10.1200/OP.21.00144
- 30. Budhwani S, Fujioka J, Thomas-Jacques T, De Vera K, Challa P, De Silva R, et al. Challenges and strategies for promoting health equity in virtual care: findings and policy directions from a scoping review of reviews. J. Am. Med. Inform. Assoc. JAMIA 2022;29:990–9. https://doi.org/10.1093/jamia/ocac022