BLACK WOMEN’S LIVED EXPERIENCE OF BREAST CANCER

INVISIBLE: THE LIVED EXPERIENCE OF BLACK WOMEN WITH BREAST CANCER IN TORONTO

By IELAF AHMED ABDIN KHALIL, BKin

A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements for the Degree Master of Public Health

McMaster University

McMaster University MASTER OF PUBLIC HEALTH (2024) Hamilton, Ontario

TITLE: Invisible: The Lived Experience of Black women with breast cancer in Toronto AUTHOR: Ielaf Ahmed Abdin Khalil, BKin (University of Toronto) SUPERVISOR: Associate Professor Dr Olive Wahoush RN PhD. NUMBER OF PAGES: xiv, 119

Lay Abstract

Little is known about the breast cancer experiences of Black women in Canada. The purpose of this study is to explore the lived experiences of Black women in Toronto, Ontario with breast cancer, in order to understand their cancer journey. In the United States, Black women are more likely to develop aggressive breast cancer and to die from their disease compared to white women. The information learned from this study will begin to address a gap in the literature about Black women living with breast cancer in Canada.

Abstract

Context: Data, primarily from the United States, indicates that Black women experience delays in breast cancer treatment, receive non-standard care, and have a lower survival rate. Canada is not immune to racial disparities, but race-based health data is not routinely collected.

Objectives: To understand the lived experiences of Black women in Canada living with breast cancer.

Methods: One-on-one semi-structured qualitative interviews were conducted with 20 women living in Toronto, Ontario who identified as Black/African/Caribbean and who were currently undergoing or had previously undergone treatment for breast cancer. Data was analyzed using an inductive, constant comparative method to derive themes.

Results: Several themes were identified including 1) the importance of social support and community; 2) importance of faith and spirituality; 3) cultural considerations; 4) mental health and psychosocial support; 5) body image and intimacy challenges; 6) importance of fertility preservation; 7) financial burden; 8) lack of representation; and 9) mistrust of the healthcare system. The overarching theme was a sense of feeling alone, unseen, and unrepresented. Recommendations include the importance of advocacy, the need for race-based cancer and health data and the need for racially concordant care.

Conclusion: Invisibility and anti-Black racism in healthcare settings are unique concerns for Black women with breast cancer in Toronto. Understanding their needs can help to dismantle medical racism and colourblind healthcare. Further research is needed to develop tools to address these inequities and work towards culturally appropriate and safe approaches.

Acknowledgements

This study would not be possible without the wonderful, courageous women who agreed to share their stories. Thank you for trusting me with your breast cancer journeys. I am truly humbled by your strength and resilience.

A huge thank you to my supervisor, Dr. Olive Wahoush, for always supporting my decisions, encouraging me and being there for the challenges over the years. It’s been quite the adventure! Dr. Andrea Covelli and Dr. Juliet Daniel, my committee members, and Dr. Aisha Lofters: thank you for welcoming me onto your research teams. I am indebted to you for guidance and encouragement. Thank you for championing me.

I am so grateful for the support of the rest of the research team, Dr. Gayathri Naganathan, Leila Springer (and the Olive Branch of Hope), Miah Zammit, Allia Karim, Ines Ndzana Siani, Maureen Saha, Dr. Frances Wright, Dr. Danielle Rodin, Dr. Tulin Cil, and the Master of Public Health (MPH) program. This thesis would not have been completed so successfully without your support.

Last but definitely not least, thank you to my parents Muram and Ahmed; my siblings Mustafa, Asma, Fatima, and Mohammed; and my precious nephew Ahmed for always being there for me. Thank you for putting up with all the emotions and changes in direction. Thank you for pushing me when I doubt myself. Thank you for being there to provide me with food and endless cups of tea. Thank you for always praying for my success and for loving me. I am blessed and grateful. *Alhamdulilah.*

Funding Acknowledgements

This research project was supported by funding from the Canadian Cancer Society (CCS), the Canadian Institutes of Health Research (CIHR), Canadian Team to Improve Community-based Cancer Care along the Continuum (CanIMPACT), and University Health Network (UHN).

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List of Abbreviations and Symbols

Community Based Research	CBR
Interdisciplinary Centre for Black Health	ICBH
Surveillance, Epidemiology, and End Results	SEER
Socioeconomic Status	SES
United Kingdom	UK
United States of America	US

List of Appendices

Declaration of Student Achievement

Recruitment of study participants was primarily coordinated by the thesis author, Ielaf Khalil, with the support of the research team. Dr. Naganathan conducted the first 5 interviews, and thesis author, conducted the remaining 15 interviews. Ielaf Khalil, Dr. Naganathan, Dr. Covelli, and Dr. Wahoush participated in the data analysis. The thesis author coded all the interviews, while the remaining researchers coded a selection of interviews and contributed to the analytic discussion. The overall research team (including Dr. Aisha Lofters, Dr. Juliet Daniel, and Leila Springer) provided feedback on the results. Ielaf Khalil is the primary author of this thesis.

Chapter 1

Introduction and Background

1.1 Introduction

Very little is known in the Canadian context about disparities in breast cancer care and outcomes for Black women due to the lack of routine collection of race-based health data. However, Canada is not immune to racial disparities, systemic discrimination or anti-Black racism. Disparities in breast cancer outcomes for Black women in the United States (US) are well documented. Data from the United Kingdom (UK), where demographic characteristics of the Black community and the healthcare system are different, also paint a similar picture in terms of poorer outcomes for Black women with breast cancer.

The purpose of this study is to broaden our understanding of how Black women in Canada experience breast cancer by exploring their lived experiences to identify challenges, barriers, and inadequacies in care. This research is important as findings may provide an understanding critical to developing actionable strategies to address inequities and biases in breast cancer care in Canada.

This study focused on the experiences of Black women in Toronto, Ontario and is part of a larger study exploring the lived experiences of Black women across Canada.

1.2 Race and Anti-Black Racism in Canada

1.2.1 Black Communities in Canada

Nova Scotia is the birthplace of Black communities in Canada, and it is where the largest population of Black communities were found until the mid-1960s. Fifty-two historic African Nova Scotian communities have called Canada home for over 400 years (Black Cultural Centre for Nova Scotia, 2021). The changes in Canada's immigration policies in the 1960s opened up immigration to Black newcomers from the African continent and the Caribbean. Today, the Black population in Canada is very diverse, with more than 170 different places of birth, and more than 200 ethnocultural origins (Statistics Canada, 2019). Ontario is home to just over half of the total Black population in Canada, with Toronto being home to the largest Black population in the country, with around 442,000 people residing in the city. (Statistics Canada, 2019).

1.2.2 Systemic Discrimination in Canada

Canada has a colonial history of slavery, which was not abolished until year 1834 (Government of Canada, 2020). This often forgotten or erased history of slavery leaves a legacy of systemic anti-Black racism. Systemic discrimination in Canada is seen in the overrepresentation of Black people in the criminal justice system (Owusu-Bempah et al., 2023); overrepresentation of Black children in the welfare system (Antwi-Boasiako et al., 2022; Cénat, Mcintee, et al., 2021; Clarke et al., 2018; Mohamud et al., 2021); and racial profiling and over-policing of Black communities (Wortley & Owusu-Bempah, 2022). These inequities are being documented in a growing body of literature.

1.2.3 Health Disparities for Black Communities in Canada

Racial health disparities exposed by the COVID-19 pandemic, highlighted the need for the collection of race-based data (R. Ahmed et al., 2021; Ottawa Public Health, 2020; Statistics Canada, 2020). In response, the University of Ottawa launched the Interdisciplinary Centre for Black Health (ICBH) in December 2021, the country's first research centre focused on Black health (Capital Current, 2021). In the same month, Dalhousie University announced the Black Studies Research Institute, a centre to support the interdisciplinary research of Black scholars (Dalhousie University, 2021). Studies conducted and highlighted by the ICBH found several health disparities. The prevalence of depressive symptoms for Black people in Canada is almost six times the rate reported for the general Canadian population (Cénat, Kogan, et al., 2021). Disparities also exist in mental health diagnosis and treatment (Cénat, Dromer, Darius, Dalexis, Furyk, Poisson, Mansoub Bekarkhanech, et al., 2023). In the cancer research sphere, there is a dearth of studies exploring cancer in Black communities in Canada but a review of the few data available suggests racial disparities in screening, incidence, and quality of care (Cénat et al., 2023). Systemic anti-Black racism and its effects on the health of Black communities in Canada can no longer be denied (Dryden & Nnorom, 2021).

Chapter 2

Literature Review

2.1 Breast Cancer Disparities

Information from the US, where race data is routinely collected, indicate cancer disparities for Black women along the breast cancer journey, from screening to diagnosis to treatment.

2.1.1 Breast Cancer Screening and Diagnosis

Disparities for Black women with breast cancer in the US exist for both breast cancer screening and diagnosis. Studies using Surveillance, Epidemiology, and End Results (SEER) data, indicate that Black women are less likely to be diagnosed with early-stage breast cancer (Lantz et al., 2006); more likely to be diagnosed at an advanced stage (Azin et al., 2023; Hardy & Du, 2021; Ko et al., 2020) and are more likely to have larger tumor size at diagnosis (Hardy & Du, 2021). Reports indicate that racial disparities in screening mammography exist, as Black and Hispanic women in the US have lower utilization rates compared to white women (A. T. Ahmed et al., 2017). A US study using National Comprehensive Cancer Network (NCCN) data found that time to diagnosis for symptomatic patients was longer for Black women (53.6 days compared to 36 days for white women); time to diagnosis through abnormal mammograms was also longer for Black women (29 days compared to 21 days for white women); and Black women had the highest proportion of advanced disease (Stage III or IV) compared to all other groups (Warner et al., 2012).

2.1.2 Breast Cancer Treatment

Disparities also exist at the treatment stage for Black women with breast cancer in the US. In one US study, young Black women were more likely to have treatment delay times of more than six weeks after diagnosis, compared to white women (Smith et al., 2013). Black women are also less likely to receive surgery (Bradley et al., 2002; Hardy & Du, 2021); and more likely to not undergo breast reconstruction (Azin et al., 2023) than their white counterparts.

2.1.3 Breast Cancer Mortality

Findings on disparities in breast cancer mortality for Black women in the US may be the most troubling. One study looking at invasive breast cancers found that Black women with small-sized tumours were more likely to die of breast cancer than white women, even when adjusting for income (Iqbal et al., 2015). Longer treatment delay times for Black women, in the study mentioned previously, were significantly associated with decreased survival time (Smith et al., 2013). Disparities in mortality also exist for older Black women, as they have worse survival rates than white women (Curtis et al., 2008). One US study examining the social determinants of racial disparities in breast cancer mortality identified barriers associated with poverty, culture, and social injustice for Black women (Gerend & Pai, 2008). Barriers included: lack of a primary care physician, inadequate health insurance, poor access to healthcare, a general mistrust of the healthcare system, racial profiling, and discrimination (Gerend & Pai, 2008).

Despite the significant progress made to decrease breast cancer mortality overall since the 1980s, a significant racial disparity in breast cancer mortality remains for Black women in the US. The mortality rate for Black women is 40% higher compared to white women and two-fold higher for women younger than 50 (Giaquinto et al., 2022). Another significant factor for Black women is the disproportionate effect of triple-negative breast cancers. Triple-negative breast cancers are an aggressive subgroup accounting for 10-15% of breast cancers, with significantly higher rates seen in Black women, especially those who are premenopausal (Cleator et al., 2007). Compared to white women, Black women with triple-negative breast cancer tend to have earlier onset of diseases, more advanced stage at diagnosis, and more aggressive phenotypes (Siddharth & Sharma, 2018). In addition to the higher incidence of the disease, Black women are nearly twice as likely to die from triple negative breast cancer compared to white women (Howard & Olopade, 2021).

2.2 Limited Canadian Information on Race and Breast Cancer

Race-based health data is not routinely collected in Canada. However, Black communities and their allies have been advocating for the collection of race-based data or disaggregated data to better identify disparities and highlight inequities. Racism is a social and structural determinant of health and healthcare (Ramsoondar et al., 2023) and a fundamental cause of health inequities and adverse health outcomes for ethnic and racial minorities (Williams et al., 2019).

2.2.1 Breast Cancer Screening and Diagnosis

While there is a lack of Canadian data on prevalence and mortality of breast cancer for Black women, researchers have been able to use immigration data to examine health inequities for immigrant women. A scoping review by Nnorom et al. (2019) highlighted inequalities in breast cancer screening for immigrant women from sub-Saharan Africa. Immigrant women in Ontario are less likely to have screen-detected breast cancer and have a longer median diagnostic interval compared to their Canadian-born counterparts (Lofters et al., 2019). Another study focusing on urban centres in Ontario (population over 100,000 people) found that breast cancer screening rates were lowest among new and recent immigrants compared to Canadian-born women and older immigrants (arrived before 1985) (Vahabi et al., 2015). Immigrant women from a Muslim majority country, specifically those from Sub-Saharan Africa and South Asia, may also have lower breast cancer screening uptake compared to those from non-Muslim majority countries in Ontario (Vahabi et al., 2016). Several barriers to breast cancer screening among immigrant populations in Canada, reported in a recent scoping review (Ferdous et al., 2019) include, lack of education, lack of doctors' recommendation, the preference for a female doctor, embarrassment, and the inability to speak English or French.

A study examining Haitian immigrant women's access to the provincial breast cancer screening program in Quebec found that there may be social inequalities in breast cancer screening for immigrant Haitian women in Montreal due to the written communication used (Raynault et al., 2020).

Two Ontario studies found that immigrant women may be diagnosed at later stages. Lofters et al. (2019) found that women from the Caribbean, as well as those from Latin America and South Asia, were diagnosed at a later stage than their Canadian-born counterparts. Findings from an earlier study examining women with invasive breast cancer in Ontario supported this, as they found that immigrant women were less likely to be diagnosed with early-stage disease (Iqbal et al., 2017).

2.2.2 Breast Cancer Treatment

A recent study also found that immigrant women had longer wait times between surgery and radiation therapy, with women from the Caribbean and Latin America having the longest wait times (Eom et al., 2023). Immigrant women are less likely to receive radiation therapy after breast cancer surgery compared to Canadian-born women and long-term resident women in Ontario (Eom et al., 2023). In Ontario, a study on symptom burden for women undergoing breast cancer surgery found that immigrant women, specifically from Sub-Saharan Africa and South Asia, were more likely to have a higher burden of pain (Parvez et al., 2023).

2.3 Study Problem and Rationale

Disparities in breast cancer outcomes for Black women in the US are well documented. Information from the United Kingdom (UK), where demographic characteristics of the Black community and the healthcare system are quite different, also paint a similar picture of poorer outcomes for Black women with breast cancer. Black British women present with breast cancer 21 years younger than white British women; with younger Black women having more aggressive tumours; and overall Black women were more likely to die (Bowen et al., 2008).

Very little is known in the Canadian context about disparities in breast cancer care and outcomes for Black women due to the lack of routine collection of race-based health data. However, Canada is not immune to racial disparities, systemic discrimination or anti-Black racism. This study was conducted in Toronto, home to Canada's largest Black population, and thus ideal to explore the experiences of Black women with breast cancer. The growing diversity of the Canadian population necessitates addressing the information gaps about Black women and breast cancer.

2.4 Study Objective and Research Questions

This study seeks to broaden our understanding in the Canadian context of how Black women experience breast cancer in the Canadian context. Exploring the lived experiences of Black women with breast cancer in Toronto will improve our understanding of how race and sociocultural factors shape the cancer journeys of Black women and describe the challenges, barriers, and inadequacies in care that they experience.

The specific research questions of this study are:

1) What are Black women's experiences of breast cancer screening, diagnosis, treatment, and surveillance in Toronto?

2) What challenges, barriers, and inadequacies do Black women with breast cancer face in Toronto?

Chapter 3

Methodology

3.1 Paradigmatic Position and Theoretical Underpinnings

This qualitative narrative study about the breast cancer experiences of Black women in Toronto was informed by a social constructionist paradigm. The purpose of constructivist inquiry is to understand and reconstruct (Guba & Lincoln, 1994). Knowledge is understood to be socially constructed, as well as historically and culturally constituted (Braun & Clarke, 2021). This paradigm, or worldview, encompasses the ontological assumption that reality is shaped over time by social, cultural, gender, and other factors (Guba & Lincoln, 1994). This allowed for a deeper understanding of how Black women socially construct meaning and was important in order to stay loyal to the experiences and voices of participants.

3.2 Rationale for Study Design

3.2.1 Narrative Inquiry

Due to the dearth of research exploring the lived experiences of Black women with breast cancer, an explorative qualitative study, using a narrative inquiry approach was most appropriate. Narrative inquiry allows for rich, contextual descriptions (Lieblich et al., 1998; Trahar, 2013). The approach is used in many disciplines to explore identity, culture, and historical experiences (Lieblich et al., 1998). In the social sciences, narrative inquiry has been used to study minorities and groups that are frequently discriminated against (Lieblich et al., 1998). This approach allows for silenced voices to be heard and is political in purpose, by challenging established ways of thinking (Trahar, 2013). It is increasingly being used in nursing research, due to its ability to provide an "insider view" by providing detail of personal experiences (Wang & Geale, 2015).

3.2.2 Community-Based Research

Formulation of the research question, methodological design, and tool formulation were guided by principles of community-based research (CBR). CBR is a collaborative research approach, increasingly used in public health, that aims to equitably involve community members and representatives in every aspect of the research process (Israel et al., 1998). It draws upon both critical theoretical and constructivist paradigms (Israel et al., 1998). Some of the key principles of CBR are recognizing the community as a unit of identity; building on the strengths and resources that exist within the community; facilitating collaborative partnerships with community at all levels; promoting a co-learning and empowering process to address social inequalities; and disseminating knowledge and findings to all community partners (Israel et al., 1998).

3.3 Positionality and Research Team

The author of this thesis joined this research project in January 2022. At that time, the larger research study examining the lived experiences of Black women across Canada was underway. The research team consisted of Andrea Covelli (AC), the principal investigator, a breast surgical oncologist and qualitative researcher with an interest in health inequities; Dr. Aisha Lofters, a family physician and scientist who has published extensively on cancer prevention and screening; Dr. Juliet Daniel, a cancer biologist with local and international expertise in cancer biology; Dr. Gayathri Naganathan (GN), a surgical resident with qualitative research expertise in the area of health equity research; Dr. Frances Wright, a breast surgical oncologist and qualitative researcher; Dr. Danielle Rodin, a radiation oncologist with a focus on breast and global access to cancer treatment; Dr. Tulin Cil, a surgical oncologist and clinician investigator with a focus on breast; and Leila Springer, founder and CEO of the Olive Branch of Hope, a non-profit organization in Toronto that has supported Black and other racialized women for over 20 years.

Prior to this project, the thesis author had worked with Dr. Lofters on *Every Breast Counts*, a sister-project to this study, which co-developed the first online resource hub for Black women along the breast cancer journey. *Every Breast Counts,* hosted on the Women's College Hospital website was collaboration between research staff, the Olive Branch of Hope, and four breast cancer survivors from the community (Hashi et al., 2023).

3.4 Study Design

3.4.1 Interview Guide Development:

A semi-structured interview guide was developed by the principal investigator of the study, AC, in collaboration with the research team. Development of the guide was based on a review of the literature and the expertise of the research team. In addition to lived experience as Black women, two members of the team, at the time, were also breast cancer survivors. The interview guide was structured to explore the lived experiences of participants during their breast cancer journey from diagnosis to treatment, surveillance, and survivorship. Particular attention was paid to experiences within and around medical care, social networks, self-image, and race. Closing questions revolved around recommendations for improving care, advice for other Black women, and wishes for change in the future. Questions were open-ended to yield rich, in-depth responses from participants about their experiences, opinions, and feelings (Patton, 2015).

The first 5 interviews of the larger Canadian study were pilot tested with the initial interview guide. These included the first two interviews of the data presented in this thesis, as these participants were from Toronto. The transcripts of these interviews were then reviewed by the entire research team, including the thesis author, and modified to clarify certain questions. The final semi-structured interview guide (*Appendix C*) was used for the remaining interviews.

3.4.2 Demographic Questionnaire Development:

A demographic questionnaire was developed by the principal investigator AC, in collaboration with the research team. The questionnaire collected information to inform data analysis and to direct participant recruitment for a diverse sample of participants. As with the interview guide, the initial demographic questionnaire was pilot tested with the first 5 interviews and modified following research team review. The final demographic questionnaire (*Appendix D*) was subsequently used for the remaining interviews. During the interview, the interviewer shared their computer screen and completed the questionnaire with the participant. The questionnaire collected information on the participant's age, gender identity, sexual orientation, ethno-racial identity, stage of breast cancer at time of diagnosis, residential location, education, income, employment status, relationship status, migration status, number of children, and how they heard about the study.

3.4.3 Participant Recruitment

Recruitment strategies for this study included outreach by the study team members to personal networks and to community agencies; broader outreach to the community using social media; and snowball sampling. Purposive or purposeful sampling is often used in qualitative research to provide information-rich cases for in-depth insights and understanding (Patton, 2015). Recognizing the diverse nature of Black identities and communities in Toronto, the research team brainstormed how best to reach various communities in order to achieve diversity in ethnic background, SES, age, language, sexuality, religion, and residential location.

The Olive Branch of Hope (TOBOH), as the main community partner and collaborator of this research project shared the research flyer with its members. The mandate of TOBOH is to provide Black women with access to support services and information when navigating their breast cancer journey. More than 400 Black women are served by TOBOH annually. Women who learned of the study through TOBOH self-recruited by contacting the project coordinator using the information provided on the study poster (*Appendix A*). The research study was also promoted at community events, some held in partnership with TOBOH, both virtually and in-person.

The research flyer (*Appendix A*) was also posted on breast clinic floors at Mount Sinai Hospital and Sunnybrook Health Sciences Centre, where women attending appointments could obtain study contact information to self-recruit.

Members of the research team promoted the study through personal and professional networks. This included the Breast Cancer Collaborative Group and UTOPIAN (University of Toronto Practice-Based Research Network), an extensive network of family physicians within the University of Toronto that brings together care providers with academic researchers.

Social media pages were created on Facebook, Instagram, and Twitter, to share the research flyer (*Appendix A*), as well as information about the study team. The research flyer was also posted on the *Every Breast Counts* page on the Peter Gilgan Centre for Women's Cancers section of the Women's College Hospital website.

Snowball sampling was also used to recruit participants. Snowball or chain sampling refers to identifying well-situated people and asking them about how to locate key informants (Patton, 2015). Each participant was asked at the end of their interview if they knew other Black women with breast cancer who might be interested in participating. Participants were encouraged to reach out within their own networks to encourage other eligible women to participate in the study, if they were comfortable doing so.

3.4.4 Eligibility Criteria:

Women who responded to recruitment information were screened to determine their eligibility. Women were defined as inclusive of all individuals other than cis-gender men. Potential participant women who lived in Toronto were invited to participate in the study if they:

- were over the age of 18 years old,
- self-identified as Black, of Caribbean-ancestry, or of African-ancestry, and
- were currently undergoing treatment for breast cancer or had previously undergone treatment for breast cancer in Canada.

Adult women of all ages and across all stages of the disease, including recurrence, were eligible to participate.

3.4.5 Ethics

Ethics approval for this research study was obtained from Mount Sinai Hospital (see *Appendix F* for current ethics approval). The project coordinator screened participants via phone using the telephone script (*Appendix E*) to determine eligibility. If eligibility was met, participants were provided with a consent form and scheduled for a Zoom interview with GN or the thesis author. Potential participants were informed of the purpose of the study, the study design, potential risks, the voluntary nature of the study, confidentiality, and were invited to ask questions.

Participants were assigned an identifying number once they agreed to participate in the study and their personal identifying information was kept separate from the collected data. Prior to the start of the interviews, consent was obtained verbally and through the signing of the consent form. Participants were assured that they could skip any questions that they were not comfortable answering and could end the interview at any point. Due to the personal and emotional nature of the interviews, the thesis author encouraged participants to take their time and to take breaks if needed. One participant was provided with community mental health resources after the interview, at their request, as they reported experiencing emotional struggles of their cancer journey rather than the interview itself.

Interviews were recorded through Zoom and audio was transcribed verbatim through NVivo transcription. Interview transcripts were verified for accuracy by the research team and personal identifying information was removed. Digital recordings and the interview transcripts were stored on a password-protected server and on a password-protected computer. Due to hospital policy, all consent forms, recordings, transcripts, memos, and any other study data will be stored for seven years before being destroyed.

3.4.6 Data Collection

The approved research flyer (*Appendix A*) was posted in Mount Sinai Hospital and Sunnybrook Health Sciences Centre. The community partner, The Olive Branch of Hope (TOBOH) and other members of the research team shared the research flyer at community events, on social media, and through their professional and personal networks. Interested participants contacted the project coordinator through email or via the phone number listed on the recruitment flyer.

All data was collected through one-on-one semi-structured interviews were conducted virtually with participants over Zoom. Due to the social distancing requirements imposed by the COVID-19 pandemic, video-conferencing was used. With the easing of restrictions, participants were offered in-person interviews if they preferred, to which all declined. Participant consent to audio record the interviews on Zoom was obtained at the start of the call prior to beginning the interview. The audio files were then transcribed verbatim using NVivo transcription services. All but one participant opted to keep their cameras on for ease of conversation and rapport.

Participants had the opportunity to engage in one or two interviews as desired to thoroughly share their experiences. Participants who were newly diagnosed or had not yet completed active treatment often opted for a second interview after a couple of months. Interviews ranged from 40 minutes to 2 hours and 50 minutes in length, with the average interview lasting 1 hour and 23minutes. This excludes time for obtaining consent and for questions after the interview. Three participants had 2 interviews. Participants received an honorarium in the form of a $50 gift card to a retailer of their choice for each interview. Interviews were conducted between October 16th, 2021 and March 1st 2023. The first five interviews were conducted by GN. The remaining 15 interviews were conducted by the author of this thesis.

3.4.7 Theoretical saturation:

In qualitative research (Sandelowski, 1995), the number of participants is determined by theoretical saturation, the point where no new ideas, relationships, or themes emerge from data analysis and each category is well developed (Corbin & Strauss, 2008). The purpose of this study was to gather rich description to understand the lived experiences of Black women with breast cancer in Toronto. Consequently, recruitment aimed to reach a diverse population of Black women. According to Sandelowski (1995), an adequate sample size for a qualitative study is one which is small enough to allow for deep analysis and large enough to result in new and rich data. Recruitment for this thesis ended with twenty participant interviews which helped ensure rich information and deeper understanding of participant experiences.

3.4.8 Data Analysis

The first phase of thematic analysis, as described Braun and Clarke (2021) is familiarisation. The purpose of dataset familiarisation is to develop a deep knowledge of the data through immersion and to begin to critically engage with it (Braun & Clarke, 2021). I familiarized myself with the data by first listening to the audio of the interviews. I then reviewed interview transcripts while listening to the audio to correct any mistakes made by the transcription software. This involved correcting words that the software had misheard, skipped over or misspelled; as well as adding in punctuation and correcting grammar mistakes. During this step I also removed information that could be used to identify participants from the transcripts, such as personal information or specific names of physicians or hospitals. I then reread the clean versions of the interviews and wrote brief analytic notes.

The second phase, coding, is the process of systematically identifying relevant or interesting segments of data and applying descriptions, or code labels, that are analytically meaningful (Braun & Clarke, 2021). The coding approach was largely inductive or data-driven, which fit well with this project, as we are trying to explore the lived experiences of participants. I coded using NVivo software as well as by printing out transcripts and using highlighters and pens. Coding is an evolving and subjective process, driven by the meaning-making or interpretation of the researcher (Braun & Clarke, 2021). During this phase, I discussed what I was seeing in the data with various members of the research team.

Phase three involves generating initial themes, clusters of codes that share core concepts and describe broader, shared meanings from the data; while the fourth phase involves developing and reviewing themes (Braun & Clarke, 2021). At this stage I re-engaged with the full dataset and examined the relationship between themes, the wider context of the research, and existing knowledge and practice.

A constant comparative method was used in this study, as I conducted interviews concurrently with data analysis. Constant comparison refers to the process of coding and analyzing data in conjunction with theoretical sampling, or the collection of new data (Glaser & Strauss, 2017). Concurrent analysis allowed for the exploration of emerging ideas in subsequent interviews to expand the understanding of participant experiences and informed ongoing recruitment of participants for diversity of demographic characteristics and experiences.

Coding meetings with the thesis supervisor and members of the research team were conducted to discuss emerging themes from the data. Multiple views of initial coding by committee and team member with research, clinical, and/or lived experience allowed for richer and more nuanced insights and helped minimize the risk of bias by the researcher. These reviews allowed the thesis author to refine themes and affirmed the analysis. A thematic map (*Appendix G*), a visual mapping technique, was created to explore how some themes related to each other. At this stage, overarching themes, and subthemes started to emerge.

Phase five of the thematic analysis approach involves fine-tuning of themes through refining, defining, and naming (Braun & Clarke, 2021). Through an iterative process, themes were revised and reorganized. The sixth and final phase of Braun and Clarke's thematic analysis approach is the write up, where the analytic narrative is weaved with data extracts to tell the story that addresses the research question (Braun & Clarke, 2021). The results of this study are presented in Chapter 4 and discussed in Chapter 5.

3.5 Reflexivity

Reflexivity involves turning the lens back onto oneself as a researcher and taking responsibility for one's impact on research questions, how data is collected, and how it is interpreted (Berger, 2013). Personal reflexivity involves examining the researcher's values and their effects on the knowledge produced, while functional reflexivity examines how research design shape knowledge production (Wilkinson, 1988).

Throughout this study, I engaged in reflexive practice through discussions with team members and personal reflections noted in a journal. I reflected on my social location, values, and assumptions. With my research team, we reflected about our impact on recruitment and access to the research; on building rapport and trust with communities and participants; on the way questions were asked; and on our interpretations of participants' accounts.

I am both an insider and an outsider as it relates to this project. As a Black woman, and member of the "Black community" in Canada, I am an insider. As a healthy woman who has never been diagnosed with breast cancer, or any other type of cancer, I am an outsider. I am also young, able-bodied, well-educated, an immigrant, African, heterosexual and hijab-wearing. I have an uncommon, foreign-sounding, often misspelled and mispronounced name. I am brown-skinned, of a lighter complexion, and have medium-length, type 4c hair, which I wore in braids or twists or in a bun when I conducted interviews one-on-one with participants. I recognize all of my identity and acknowledge the diversity of Black women and their experiences.

During recruitment, I reflected on my intersecting identities to identify which groups I could easily access and which groups I may be overlooking; this activity promoted inclusion and helped minimize bias. As an interviewer, I reflected on the way I was able to create a safe space for participants. I conducted some of my interviews wearing my hijab, as I do in public spaces, but the majority of interviews not wearing it, presenting myself the way I would if I had a female friend over in my home. I reflected on how the decision to do this was impacted by the complexities of my own Black identity, as a Black woman who is proud of her natural, afro-textured hair, but who has also proudly worn her hijab for nearly two decades. I reflected when participants used words like “us” and “our” and when they didn’t; when one participant didn’t feel comfortable having her camera on.

Chapter 4

Results

4.1 Participant Characteristics

Twenty participants from Toronto consented to participate in a one-on-one interview over Zoom. Interviews took place between October 16th, 2021 and March 1st. 2023. The first 5 interviews were conducted by GN and the remaining 15 interviews were conducted by the thesis author. All interviews were conducted in English. Three participants completed two interviews: one stopped their first interview due to fatigue and continued the following day; two had their first interview at an earlier stage during active treatment and had a second follow-up interview months later. The average interview time was 83 minutes, with the shortest interview lasting 40 minutes and the longest interview lasting 170 minutes.

The diagnosis and demographic information collected from participants through the survey is presented in *Table 1* below. Most participants (n=14, 70%) were between the ages of 35 to 54, reflecting younger ages for a population of breast cancer patients or survivors. All participants (n=20, 100%) identified as female and heterosexual.

Stages of disease varied, eight participants (40%) were diagnosed as Stage 2 cancer, seven reported Stage 3 (35%), and the remaining five (25%) were either not given a cancer stage, were unclear, or preferred not to answer. Most participants were 1 to 5 years post diagnosis (n=10, 50%), seven (35%) were less than a year since diagnosis, and three (15%) reported that they were five or more years post diagnosis.

A number of participants were immigrants to Canada (n=12, 60%), some were recent newcomers, but most were more established in Canada. The remainder of the participants (n=8, 40%) were born in Canada. None of the participants had arrived as refugees. Most participants identified as Black (n=9, 45%), while other participants gave additional ethnic or racial identifiers. These included: Afro-Canadian, Black Canadian, African, mixed, bi-racial, Caribbean-Canadian, Jamaican, and Somali.

Relationships status varied for participants. Six (30%) were married, one participant (5%) was in common-law relationship, and one (5%) was in a long-term dating relationship. In summary eight participants were in partnered relationships. Most participants were single, five (25%) were single, three (15%) were separated, and four (20%) were divorced and single.

Just over half of the participants were mothers (n=11, 55%) with one child (n=2, 10%), two children (n=6, 30%), or three children (n=3, 15%). The remaining nine participants (45%) did not have children.

The socioeconomic status (SES) of participants also varied. In terms of education, participants most participants had completed higher education, most participants had post-secondary education (n=16, 80%). Five participants (25%) had graduate degrees, five participants (25%) had undergraduate degrees, six participants (30%) had college degrees, three participants (15%) had a high school diploma, and one participant (5%) had completed less than a high school diploma. In terms of employment, most participants (n=7, 35%) were on disability leave, four participants (20%) were employed full-time, one participant (5%) was self-employed, two participants (10%) were unemployed, two participants (10%) were retired, and four participants (20%) preferred not to answer. In terms of income, five participants (25%) made less than

$50,000/ year; three participants (15%) made between $50,000 to just under $98,000/year; five participants (25%) made over $98,000/year; and 7 participants (35%) preferred not to answer.

Table 1. Demographic characteristics of participants (N=20)

Age (years)	**n (%)**
18-24	1 (5%)
25-34	2 (10%)
35-44	7 (35%)
45-54	7 (35%)
55-64	2 (10%)
65+	1 (5%)
Gender	**n (%)**
Female	20 (100%)
Male, transgender, non-binary, prefer not to answer	0 (0%)
Sexual Orientation	**n (%)**
Heterosexual	20 (100%)
LGBTQIA2S+	0 (0%)
Stage of Breast Cancer at Time of Diagnosis	**n (%)**
Stage 1	0 (0%)
Stage 2	8 (40%)
Stage 3	7 (35%)
Stage 4	0 (0%)
Don't know/prefer not to answer	5 (25%)
Time Since Breast Cancer Diagnosis	**n (%)**
Less than 1 month	0 (0%)
1 - 6 months	2 (10%)
6 – 12 months	5 (25%)
1 - 5 years	10 (50%)
More than 5 years	3 (15%)
Highest Level of Education Completed	**n (%)**
High School diploma	3 (15%)
College Degree	6 (30%)
Undergraduate Degree	5 (25%)
Graduate Degree	5 (25%)
Other	1 (5%)
Current Relationship Status	**n (%)**
Single	5 (25%)
Married	6 (30%)
Common-law	1 (5%)
Long-term Dating	1 (5%)
Separated	3 (15%)
Divorced and Single	4 (20%)
Number of Children	**n (%)**

0	9 (45%)
1	2 (10%)
2	6 (30%)
3	3 (15%)
Current Employment Status	**n (%)**
Unemployed, looking for work	2 (10%)
Employed Full-time (>30 hours)	4 (20%)
On Disability Leave	7 (35%)
Self-employed	1 (5%)
Retired	2 (10%)
Prefer not to answer	4 (20%)
Current Income	**n (%)**
$0 - $49,999	5 (25%)
$50k - $97,999	3 (15%)
$98k - $151,999	5 (25%)
$152k +	0 (0%)
Prefer not to answer	7 (35%)
Migration Status	**n (%)**
Arrived as a refugee	0 (0%)
Arrived as immigrant	12 (60%)
Born in Canada	8 (40%)

To illustrate the findings of this study, a selection of representative participant quotations is presented in the next section. The selection illustrates both typical responses and the range of views expressed by participants. Quotes are labelled by participant number. including 1) the importance of social support and community; 2) importance of faith and spirituality; 3) cultural considerations; 4) mental health and psychosocial support; 5) body image and intimacy challenges; 6) importance of fertility preservation; 7) financial burden; 8) lack of representation; and 9) mistrust of the healthcare system.

4.2 Importance of Social Support and Community

Participants discussed impact of social support from family, friends, chosen family, and colleagues during their journey. For most participants, social support networks provided physical and emotional support by attending appointments, providing meals, financial support and advice.

Examples of support included practical support:

> *"A combination of friends and family... pitched in and was like, 'OK, let us know what you want, what you need. We're coming to drop off like meals,' or 'we're coming to drop off groceries,' ... I'm grateful and very thankful to have been able to have that. I know that's not the case for uh, for everybody and I think that compounds the situation when you throw a pandemic into the middle of it." Participant 021*
>
> *"...my aunt... and uh, so nine of my mom's female cousins have all had breast cancer, so um, as and as well as my grandmother, she passed away from breast cancer. My grandmother's sister had it um, and she passed away from it, very young, thirty-four, I believe. And so every one of my family kind of is close to it. So everyone was very supportive. Everyone that had it reached out and they were, you know, helping me and giving me advice and stuff like that. And uh my friends, like all of my close friends, um, were amazing. So it was really a lot of people that came together." Participant 039*
>
> For some participants, this included family members coming in from abroad.
>
> *"I'm originally from the UK, so a lot of - I have a lot of family and friends in the UK, so I didn't really have them around. My sister flew down for one of my chemo appointments. Um, but it's really just been kind of like friends, even like acquaintances. Like someone I work with, has come with me for chemo appointments. My kids have been there. Um, so they, you know, my daughter comes with me for appointments and chemo, and my son has been staying with me and helping out. Um, so that's kind of like been it. It has been family, friends, my kids." Participant 042*
>
> *"...my family, they've been extremely supportive. They- my sisters came. They you know basically stayed with me throughout my entire chemo, um when I had surgeries, they you know, they stay with me and they support me. My mom, she doesn't live in Canada, but my mom came and she stayed with me for a few months as well. So um my, my family has been my rock and they've really been helping me throughout this entire experience." Participant 010*

4.2.1 Not Telling Everyone

Participants discussed limiting who they shared their diagnosis with. For some participant this was attributed to pragmatism and not wanting to expend energy repeating explanations during active treatment.

> *"...among friends, I told only a handful of friends. Back to my pragmatism, I just thought, if you can't help, what's the point of bothering you with this, right? So my really close*

> *friends who are not physically close, but my really close friends, I told them, I told my daughter's godparents. Um, a then, you know, everybody else I told them, when - when I was done. Right? When chemo was done, I told everybody else then. Um, but I just didn't want the - I don't want to expend the energy of this many humans, you know? Um, and the questions and you know, uh, educating them, and I just - I just didn't want to deal with it until I was done and ready. Plus, I, I preferred to deliver good news then bad news. You know? Um, so to say it was over and that I'm good was a lot better than saying, well, there is no starting and I don't know what's happening next." Participant 037*

Another participant said she limited her social support to family and friends. She mentioned not finding cancer support groups helpful, as she was trying to maintain her positivity.

> *"[Name of Breast Cancer Organization]. I, uh, joined that support group. Uh, there was another one on Facebook, but it was tough. I don't know. I didn't - I didn't really... like it because... I don't know. For me, it just wasn't... It wasn't something that was like really helping me like, if anything, it was like because a lot of the - a lot of times, um... like it could be really dark and stuff. And and I was just trying to like, stay positive and not kind of get like overwhelmed with everything. So yeah, I kind of just - I use the people around me, close to me like family and friends as my support." Participant 039*

4.2.2 Relationship Changes

Several participants discussed the impact of their cancer journeys on their relationships, which was both positive and negative. Many explained that people they expected to support them were absent but that they received support from unexpected sources as well, such as colleagues with personal experiences of breast cancer or caring for a loved one with breast cancer. One younger participant described her anger as she watched friends go on with their lives while she was in treatment. Some participants had challenges with intimate partners.

One participant discussed the difficulties with her partner and how he made her feel during her journey.

> *"The biggest change, I would say, occurred with my partner. He was very distant, he - he made me feel like - like I had leprosy or something, he made me feel like the cancer was*

> *contagious. He separated himself from me. Even as much as sleeping in a separate room. So I really felt... I felt ugly [laughs]. I felt like he just didn't want to be near me. You know, just because, you know, I had lost my hair, you know, so already, I'm already dealing with with the changes happening to my body and to my - to my overall appearance. So to have someone who's supposed to be your partner almost be disgusted by you, I was - was difficult. And I'm not saying that's how he felt, but that's how he made me feel." Participant 001*

Another participant explained how her marriage ended during her journey and the experience was difficult for her partner as well.

> *"Yeah, he was here for the first three months of my diagnosis, and he was on paid family leave. But then he had to go back to [city] to go back to work. And uh he ended up being unfaithful, and so that's why the marriage ended. But it was - I know it was hard for him, for sure, because it was a lot and I'm sure like he was scared and stuff as well." Participant 039*

Some participants spoke about the support from their partners or ex-partners. One participant discussed the positive impact on her relationship and how her journey made her grow emotionally closer to her husband.

> *"I'd say my husband and I got a lot closer. Um, I found one of those rare Black men who's uh... emotionally available. You know, so... I mean, I would say that we grew more intimate, at a point in time, because in chemo, there's no physical intimacy, you know? But we grew a lot more emotionally intimate throughout that time. Um, and again, point of privilege and gratitude, because I know that's not been the experience for a lot of women, especially when it comes to illness and a body part that's highly sexualized. You know? Um, I think I cried the first time he kissed my scar, you know?" Participant 037*
>
> *"…my partner, who I was with while I was diagnosed, we actually broke up. I think it was…two weeks before (laughs) I found, I found the lump in my breast. But he was extremely supportive throughout…when he found out, like he came to my appointments. He came to my…chemo appointments. He was there. He, you know, drove me wherever I needed to go. Um and he basically like held my hand through the entire process. And then at the end of it, then you know we kind of went our separate ways…I mean, we're still in touch now, we we're still friends. But um while we did break up, I'll say he didn't abandon me, if you will, during that period." Participant 010*

4.3 Importance of Faith and Spirituality

Faith and spirituality were mentioned by nearly all the participants and the importance of faith and spirituality on their breast cancer journeys. Some participants spoke about their faith being there when their support systems were lacking and described examples of practical help and support including physical care.

> *"…Huge. I think if I didn't have faith, I'd be lost. Faith has pulled me through." Participant 043*
>
> *"To be honest, I really didn't have much support. The only place I could turn was, was to my faith…It allowed me to talk to God to - to cry out, because really at 3 a.m., when I can't sleep from the pain or when I can't, when I feel nauseous, there's no one to pick up the phone and call. There's no one around, you know? So really my faith, God was the only thing I had to - to cling to." Participant P001*
>
> *"...I definitely pray a lot more, for sure, a lot more...And it's definitely helped me like, you know, get through everything." Participant 039*
>
> *"Critical…I have no challenge telling people about my experience of faith and recognizing a sense of grace that was extended to me and the opportunity for me to extend grace and this sense of knowing, the sense of... I'm going to be OK. There is reason to this. It's, you know, it's not total randomness, you know? You know? I believe very strongly in a God who cares about what I'm going through. And so to be able to pray, to have others pray for me, um, gave such a sense of... quiet, calm hope through the process. I don't know... how I would have managed without my faith internally, or the expression of my shared faith from my friends who stepped in and helped. Yeah.... Yeah, it was extremely important." Participant 037*

For some participants, faith practices were not religious, but spiritual ones.

> *"I meditate a lot. I do a lot of meditation…and I think- generally, I try to um be as positive as I can." Participant 010*

Another participant expressed the importance of holism, spirituality, and healing practices in her journey.

> *"...we look at the whole picture of things and for me for this this journey it's just not the treatment of chemotherapy that I'm focusing on, it's the entire piece of things. So it's the mind, the body and the spirit. So I've been focusing a lot on meditation, that has helped*

> *me get through some of the high anxiety periods, times where I'm pushed into these machines, the C.T. scanners, MRI machines. I've used deep breathing to get through all of those sessions. Reiki has been a great healing um practice that I've also incorporated that I feel has really helped me focus, and um I know not a lot of people know of these types of things, but that focuses on the spiritual senses of things as well as prayer and reading my Bible and using those scriptures to help motivate me and propel me into having positive thoughts, all of which I think are important. It's not just the the treatment piece of things, it's everything." Participant 043*

Many participants spoke about faith and how their experiences had changed them and given them a new purpose.

> *"...So I pray and I uh...sometimes I, you know... get angry with God. Sometimes I, you know, say, 'I'm sorry, I got angry.'...It does play a role in it and I do believe that um, I will get through this. I do believe I will. And I just have to know what...how it's going to change my life, um, and in which ways and um what I'm going to do with what I have experienced in this cancer journey. Yeah . So it's not just to... um... it's not just to go through it. It's to go through it and be a different person." Participant 042*

> *"I'm still learning patience and trust, but I do trust God, and I know that this is not the end. This is more so a catapult into what I'm meant to do next. I've always felt as soon as I got this diagnosis that I was going to use this to teach somebody else…it stopped me dead in my tracks to really re-evaluate life. And faith has been a big part of that. So I'm trusting God and His, His, His way of being to guide me to the right people I need to be speaking to to heal." Participant 043*

> *"...I'm actually thankful for the journey that I went on. The journey enabled me to do some introspective work. It enabled me to quiet myself. It enabled me to really reflect on my life and recognize some changes that um that I needed. And I think had it not been for the journey that I went on and the quietness and stillness, maybe I would not be where I am today with my emotional growth. And, you know, so I'm thankful for the time that I had because it allowed me to be still." Participant 001*

One participant, the only Muslim participant, spoke of her religious and cultural belief that illness is a test from God. She also explained how she struggled and continues to struggle with some of her feelings.

> *"...a disease like this is like a test from God. Um, that's something that, like religiously um... is what a lot of... what my Muslim community and also like just Somali women in general believe…I think so as well, myself and um... Like, I remember thinking... that just made me feel very... deserving of the disease like um, that, I, I should hold this... struggle with an honour, in a sense…which, by the way, was very invalidating, I think…It's just*

> *kind of a struggle. I still, I still um, I feel like I still struggle with that till this day, um, feeling like I deserved... to go through what I did." Participant 019*

For many participants, communities of faith had a significant impact on their journey. Collectively these participants spoke about the emotional and social support they received from their faith communities.

> *"I believe very strongly in a God who cares about what I'm going through. And so to be able to pray, to have others pray for me, um, gave such a sense of... quiet, calm hope through the process. I don't know... how I would have managed without my faith internally, or the expression of my shared faith from my friends who stepped in and helped. Yeah.... Yeah, it was extremely important." Participant 037*

For some participants, this support extended far beyond spiritual and mental health support.

> *"I had a community of faith as well. I belong to a church. I, I also know of a Christian pastor that who also does who also does psychotherapy. So I was able to, you know, have an outlet that way as well as like I said, as the church. The church was there for me. And more importantly, and [laughs] I want to stress as well that there were two individuals and they were actually seniors. They were well into their 60s or 70s, and they were my backbone. They actually took me to my appointments. They… were instrumental and just to repeat again using that word. But those two individuals were coming over. They were helping me wash the dishes. They were - the the lady the female gave me a sponge bath because I couldn't even bathe myself. I was so weak. She brought food as well as the pastor. She brought food for me. So the church also dropped off some food and things like that. So... I couldn't have really gotten through without the help of those individuals." Participant 001*

Many participants spoke about staying positive and keeping a positive mindset that stemmed from faith or was related to their faith or spiritual worldview. For some this was essential for coping with their illness.

> *"I'm literally starting again…it's been it's been quite tough, um... I've just tried to be strong and to be positive." Participant 042*
>
> *"And I do have positive vibes in regards to that…I'm building my team of, my dream team I call them of health professionals is important I think." Participant 043*
>
> *"I was just thankful that it did not run away all over my body, you know? …It's not nice to know that you have cancer. Nobody want to know that they have cancer…But you have to*

> *realize that everybody have something. You know, some people, you know, are diabetic. Some people have stroke. Some people have heart attack. Everybody have something, you know, so. You - you know whatever you have, you have to just know to just be strong and and and... you know, it's something I have to live. There's nothing you can um... you can do about it so…You know, I am very fortunate that I am still hanging in there, you know?" Participant 022*
>
> *"…generally, I try to um be as positive as I can. I think that's- like that's just my personality anyway. I know that doesn't work for everyone. Um but I- yeah, I just, I try to stay positive and try to um meditate and just reduce my anxiety and stress levels as much as I could." Participant 010*
>
> *"Yeah, probably, especially when I lost my hair and I looked really sick. You know, I could see that people were... felt bad for me, but I was - I tried to just, like, live the same way I always did and stay positive and everything…" Participant 039*

Several participants' comments about their symptoms and circumstances also highlighted their positive outlooks.

> *"…hot flashes were not fun, but not having my period for months, I was OK with that. Um not having to shave my legs also OK with that, you know?" Participant 037*
>
> *"…the only good thing about it coming back, they tell me that it is just... just right where lump is…It don't go on anywhere else. It don't spread anywhere else in my body. It is just just a lump, right?...It's not anywhere else. So that's one good thing about it… my daughter was able to go with me and stuff like that, so I was kind of lucky I got this surgery done before the COVID kicked really hard…So I was very fortunate. I get God good for that." Participant 022*

Participants also discussed staying positive when discussing advice they would give other Black women dealing with breast cancer.

> *"... because this help me, a lot, my belief…and be strong and be positive and just think that it's one phase and will pass because then you are there…So, try be strong, be strong, be positive…" Participant 036*

One participant mentioned that faith, religion, or spirituality did not play a role in her journey.

4.4 Cultural Considerations

Participants discussed common cultural beliefs about cancer, such as the taboo nature of cancer and the belief that a cancer diagnosis was an inevitable death sentence.

4.4.1 Cancer as a Death Sentence

Many participants spoke about the common cultural belief that cancer is a death sentence, which caused extreme fear for some participants upon diagnosis.

> *"Older folks think it's a death sentence, and it's not. If caught early, it's not." Participant 043*
>
> *"...and the cancer scared me more than the [chronic illness]. And the [chronic illness] affect every organ: my skin, my lungs, my heart, my kidney. Everything. And I had breast cancer and it scared the hell out of me. Put me into a shock. Yeah. It scared me more than anything. As I said, it, it's out there. It's in your face saying, this is what it is, but we - me, most of us, my community, receive it as a death sentence. Whatever people want to say, 'oh no.' Yes, we do. No matter what it is, you have your cancer in your nail? They see it as a death sentence. That's horrible isn't it? I'm not even going to beat around the bush. 'Oh you're going to die.' 'Oh Jesus, I hope you don't die.' So we need more knowledge to say it is not... We need things to say it is not…We need to talk about it more." Participant 011*

Another participant discussed her community's belief that cancer is a death sentence and how she felt like they were mourning her while she was still alive.

> *"...like the grieving part, um... I feel like within my Somali community, like, we're just going to disregard the Muslim community for a second. Within my Somali community, they think cancer is a death wish. Like there's no cure. That's it. They don't believe in medicine. They only believe in natural remedies and prayers to God. And so, that's what I meant when I said that I felt like they were grieving. Um, even though that I'm still here. It's actually crazy…my friend, who's a Somali girl... um, she actually just got diagnosed with uh cancer. It wasn't breast cancer…And you know, she was saying the same thing. She - she actually put it into perfect words. She said um, 'Do you ever just feel like you're still here, but people are grieving you?' And I was like, 'Yeah. Why do we do that? Why does our community do that?' And it's just because like, they mourn and they just... they hit their chests and they and they, you know, they pretend like you're not here, when you're still there. Uh, and it's very like, frightening, um, and not reassuring whatsoever at all." Participant 019*

4.4.2 Cancer as Taboo

Several participants spoke about not sharing their diagnosis widely and the cultural tendency to hide or not speak about cancer. One participant explained the belief about not sharing your cancer diagnosis widely, as not everyone in the community has your best interests at heart.

> *"So there are certain beliefs that, 'oh, don't put your story out there. Not everybody has your... has your interest at heart,' you know that kind of thing. I know when I was setting up this support group, because quite a few of my friends here were saying, 'put a support group together so you can post in the chat about how you're doing or whatever.' I know one of my friends said, Oh, don't do that. Not everybody's your friend on not only what is your interest at heart.’ So there's that thought that, you know, some people, even though they, they, they're pretending to be your friend, they're not really your friend…I haven't told certain people that...I don't know how much... they... have my interests at heart. I probably told more people than a lot of people in my culture.” Participant 042*

This participant mentioned that she hasn’t told her elderly mother about her breast cancer diagnosis and was encouraged by other family members not to share the diagnosis with her.

> *“…I haven't told my mother, I've got cancer um, mainly because of her age, and I just didn't want her to be stressed out. I didn't want her to be calling me every day to say, ' how are you doing?' you know, and that kind of thing. And you know, to then take the prayer to her church, I didn't want all that…you know, people back home said, 'don't tell your mom, don't tell your mom, don't tell your mom.' So, so I didn't tell her.” Participant 042*

Several participants mentioned that after they shared their diagnosis, others in their circles revealed their own hidden experiences with cancer.

> *“My culture, they're very secretive about things like this, yeah. I know one of my very good friends that I told um, she had colon cancer. She never told me she had it. And she had it about three years, three or four years ago now, maybe a bit longer than that…when I was talking about mine, that's when she was telling me…people are just kind of like, they just don't want to put their stories out there." Participant 042*

Several participants discussed the importance of looking put together, healthy, and like themselves so that they could keep their illness hidden.

> *"I'm not sure I was probably trying to keep the cancer hidden, a secret." Participant 001*

Breaking the Taboo

Many participants spoke about speaking up about their experiences in order to break the taboo and help other women in the community.

> *"I'm trying to bring awareness. I'm trying to help women coming after me. I'm trying to open the eyes and open the airways and just open convers- open up conversation about what we need to do as Black women and what we shouldn't do, which is what I did was crawl into a corner and, you know, seclude myself. It's necessary for us and for women to learn from my errors in the way that I handled it, to help them open up, to encourage them to open up. Because there's there's - there's resources out there that we just have to tap into by asking a question and by speaking up." Participant 001*

Views were mixed about whether the taboo nature of cancer was changing or not. One participant spoke about how the tendency to be secretive may be changing now.

> *"Women... with particularly cervical, ovarian, breast, sexualised areas of our bodies, right? Um, it's always seen like you brought it on yourself. You know? Nonsense, things like you probably had sex too early. You know? Um, definitely people feeling like these things are contagious. It's a lot of ignorance. Um, thankfully I did not experience that with my particular family members. But I think if I went home in that situation, I would - I would have met it with a lot of highly ignorant comments. Um, but yeah, that's definitely - there's definitely a culture around shunning and even outside of um, cancer, you know, hiding children that have disabilities. You know, it's not - I don't see that happening now. But when I was a child, people hid their children in a room. Like brought food to them, imprisoned them. Right? Um...Yeah. Shunning is a real part of, you know, the process and the concern." Participant 037*

4.4.3 Fear of Mammograms

Other cultural beliefs included fear or ambivalence towards breast cancer screening. One participant discussed the fear around breast cancer screening in the community, including her own fear due to discomfort.

> *"I lived in fear of the mammogram test. Fear, people put fear on people over the mammogram. I think they scared them away from it. It wasn't as bad but it still is really uncomfortable." Participant 008*

4.4.4 Cultural Foods

Several participants spoke about the importance of eating cultural foods on their journey. This included challenges to eat healthy and lack of information on nutrition that acknowledged their cultural identities.

"Even the food that - that she brought me was food that I'm familiar with. And that's that's nourishing for the body as well, you know, because we are very high on ground provisions like things like yams and sweet potato and green bananas and things like that, which give us a lot of nutrients and energy that we need. We grew up on those things. So to have have someone bring the food that I'm familiar with, it really makes a difference." Participant 001

"...to understand um the the molecular and diet piece of things I guess, too. Because that plays a huge role in healing, but also with prevention is the diet piece…being Afro-Caribbean, Canadian-born, there's a lot of my foods that I'm not eating anymore. So a roti. I mean, I'm still eating curry, but in a different form…I feel like I'm missing out on my culture because I'm having to now eat healthier, which is great. But it's omitting that piece of me, culturally, that's absent. So that's what I'm still striving to figure out. How can I adapt what I've originally eaten into things that are more nutritious, moving forward…I don't want to lose that part of myself. My culture is very important to me, so I still want to, and still feel like I'm a part of it. Maybe not eating all of the bad foods all the time with flour and stuff like that, like the rotis and all that stuff, but make it more nutritious, but also keeping true to my my culture." Participant 043

Several participants mentioned that they wanted race-specific information and to be directed to organizations that catered to their racial and cultural background.

> *"...provide literature - seek literature that that deals with other ethnicities. Because…cancer isn't White, cancer isn't Black, cancer affects everybody. So I think that having the resources that covers various nationalities would help. And having the resources where they can reach out to for their type of ethnicity. For example, if they they had something in the care packages that included the Olive Branch of Hope, you know, a care package that might have maybe something for Asian, you know, so it just needs to broaden. They need to broaden their scope a little bit." Participant 001*

4.5 Mental Health and Psychosocial Support

Participants discussed mental health concerns and the emotional toll of their breast cancer treatment and the need for psychosocial support. One participant discussed her anxiety and her ongoing struggle to manage it.

> *"I have a little bit more anxiety than I did prior to cancer. That one's natural, my doctor says, but you know it's not fun (laughs)…I was never like a person who had anxiety and um I just, I don't do well with it. I just don't know how to manage it, I don't- like meditation doesn't help, nothing really helps. So that's, so that's something that still impacts me um anxiety." Participant 010*

Several other participants also spoke about their fears around recurrence.

> *"There is no part of my life that's not affected by breast cancer…It completely changes everything... You know? And uh, you never quite get rid of the wondering if the damn thing will come back. You know, so... There is no part of my life untouched by it." Participant 037*

4.5.1 Loneliness

Several participants spoke about the loneliness of their journey. They mentioned their own experiences as well as concern for other Black women with less social support.

> *"...I found the biggest part of my journey has been the loneliness. Yeah. So maybe that will be something that I will see how I can support people in this journey. It's been the loneliness. And that's me that I, you know, I have people. But what about people that don't even have kids, and kind of like don't have family or they're new immigrants to Canada and they don't have anyone here. Like yeah. It's the loneliness. Yeah. It's a loneliness. Yeah... It has been family, friends, my kids. But they're not here all the time. I have to be honest. They're not here, they're not here all the time. Um, my kids both work full time, so they're out all day. My daughter doesn't live with me, so she is when she pops round. So it's been a, it's been a, it's been a lonely walk." Participant 042*

> *"...support groups are great, especially if you don't have maybe like family, close family or friends that you can lean on, then like the support groups are really amazing. Um, it was nice to know that there are other young women for me uh, that are going through it. Like, I think I felt really alone because I was so young." Participant 039*

Another participant offered advice to Black women dealing with breast cancer addressed this loneliness.

> *"...Just like try not to feel like you're the only one in the world…Try... to understand that there is a community um out there that are in the same position that you're in. Um, so what I mean by trying not to feel like you're the only one in the world, but there are other Black women, also go through breast cancer and you know, who also survive even though you don't see those statistics and you don't see those success - success stories because we're just bombarded with white women on brochures and infomercials, um, that like, there's still a chance and hope for you and to not um believe what this... what this... very um... what is the word that I'm looking for? [laughs] without sounding like offensive. This very white world [laughs] is, is like trying to paint out your feelings. Um, what they're trying to do, like just try not to - to feel as though like you're, you're the only one." Participant 019*

This participant also discussed having mental health challenges and the complex role that her faith played in her journey.

> *"...of my faith that gives me support, you know, like the Quran… things like that. But at that time, it was a little bit more complex than that because um, I wasn't allowed to process my feelings... without being reminded that um... that I am somewhat deserving of this disease, if that, if that makes sense. I just, I just wish at that time, in the beginning, I was allowed to process everything um in a more healthy way rather than... it almost felt as though it was like toxic positivity. Um, and I know that my community obviously meant well, but um, I think ultimately it kind of backfired uh for me and my mental health at that time." Participant 019*

4.5.2 Impact of the COVID-19 Pandemic

Participants who went through active treatment during the COVID-19 pandemic spoke about restrictions. They often went to appointments alone. For those undergoing chemotherapy, most participants were allowed one person to be with them for the first visit. For one participant this was not the case, and she was alone for all her chemotherapy sessions.

> *"I was alone for everything. So every appointment I was by myself, chemo was by myself. Um, yeah, I went through the whole process alone. Like even my diagnosis, I had my mom and my husband on FaceTime outside in the car…that was tough, but um we got through it so honestly for me, during chemo, for example, like just seeing older people*

> *going through the same experience, like them being by themselves, made me - made me sad because for them, it's like, you know, you don't know what stage they're at and like these might be their last days and you know, and they don't get to spend it with family. So that was tough… it was very isolating because I think that had I been going through it when COVID wasn't an issue like I would have been able to at least get out of the house, go see a movie or go for lunch. Like do things that kind of get your mind off of it, but because everything was shut down, it was just kind of like - I was just home all the time and left with my thoughts. So in that way, yeah, it was - it was tough not being able to, like, have distractions, everyday distractions." Participant 039*

In this situation COVID-19 restrictions meant little or no relief from loneliness. Another participant described how risks of COVID-19 limited her ability to support her daughter during treatment. This woman stayed with her daughter at the beginning of her treatment but was forced to move back home alone for fear getting ill from her grandchildren.

> *"I was at my daughter maybe for a good six months before I come home. ...Yeah because through the COVID, and they have three children and…they are in and out…So she said, 'You know what, mom, is best you go back home because you are alone so, you don't have to worry you're gonna catch anything from anybody.'...so I come back home, or else I would be still there." Participant 022*

4.5.3 Overwhelmed and Exhausted

Participants spoke about the overwhelming and exhausting nature of their journeys. One participant explained the experience of receiving her diagnosis, while she was still grieving the death of her mother, seemed like an out of body experience.

> *"It was numbing. It was scary. It was [sighs] um had me feeling very confused. It was a stun to the system, to be honest with you. My daughter was with me when I received the diagnosis. And I think that I pretty much went limp. And I, I, I mentally blocked out, like, I just heard voices speaking, which was my daughter and the surgeon talking about the diagnosis that was just uncovered. But I was zoned out [laughs]. I could just hear the voices, but my mind went somewhere else." Participant 001*

Another participant explained the overwhelming nature of the continuous appointments compounded by a transition period in her life and the COVID-19 pandemic.

> *"It was just stressful, like for everybody involved, because we just didn't know what the outcome would be and it was like such a long process and so many appointments, and it was just kind of like exhausting. Um, but - but yeah, I think it was just... it was overwhelming to like kind of be dealing with that, also being not in our home in a way like we had just moved into our house, just got married and it was just such a big change. Like all of a sudden, we're here in Toronto in the winter, like he'd never even like been anywhere in the winter and being stuck inside with COVID and staying with my mom. So it was like the three of us, which was just, I think he was probably like, just really overwhelmed with everything, as was I, just physically and mentally and stuff…but it was definitely, I can assume, hard on everyone." Participant 039*

4.5.4 Cancer Support Groups

Many participants used cancer peer support services during their journey. One participant mentioned that she attended a breast cancer support group once with her sister and did not return.

> *"My daughter did look up a group of people that have breast cancer…But to be honest, I go there one time and I never go back and I don't know why. I just never go back. Just one time I go and sit with those people and me and my sister and talk… It was nice. It was something I should continue, but I don't know why I didn't keep it up." Participant 022*

Other participants spoke about attending cancer support groups and the benefits.

> *"I've done um the support groups, so there's one that I was going through, through [Name of Cancer Support Organization 1]. There's [Name of Breast Cancer Organization 1], that, that one's for- targeted towards younger women, that one I'm a part of as well. And um there's…[Name of Breast Cancer Organization 2], they have um support groups and other things like that- other activities and events. So um those have been helpful, just speaking to other people who have obviously had the same experience um, it has been extremely helpful." Participant 010*

> *"…so I did this um support group that wasn't necessarily traditional. Uh, it was called [Name of Program] at [Name of Hospital 1] and it was basically an initiative where they would give us journals and cameras and they would give us a theme of the week. And so we would go along our week and we would take um pictures of whatever was the theme…that was super helpful at the time because I didn't know, like even though I was in a children's hospital, I felt I was like 17 turning 18. More times I was 18 than I was 17 when I was sick. So, I felt like I was always on the ward full of babies and like, I didn't really see teens with cancer, to be honest. And most of them were in remission and had long hair at that point. And I was still the only patient, um, you know, still connected to a pole and on a wheelchair coming to sessions every week. Um, but that was super helpful*

> *at the time because it was very distracting and we were even able to exhibit um, our pieces to like a couple of news outlets to like the doctors and nurses. Um, and my photo was on that floor for like two years I think so. That was pretty cool." Participant 019*

However, at another cancer support group that she attended she explained how she felt silenced.

> *"...I went to a support group where... I was looking for some relief, um, a few years after treatment, and so this is a point where my hair is growing back, but nobody can really tell because I was wearing a hijab. And um, we're all talking about losing hair and this lady that was sitting beside me, she was a white woman [laughs], she uh was talk about her experience and then she just pointed at me and she said, 'I bet it wasn't like... that hard for you. Like, it must have been so easy, like.' She was trying to say it in a way that like 'oh these these pretty little scarves that you wrap around your head like, in - it's you know, so stylish. It must have been not that hard for you.' Um, and I felt as though that I was silenced before I was even able to share my experience. Um, I didn't even get a chance to talk yet. She used her position and her opportunity to speak and go and share, to just like, dominate over my time, prematurely. Like, she didn't have even allow me to speak about it. Yeah. So, that was super frustrating." Participant 019*

4.5.5 Unmet Need for Mental Health Support

The importance of mental health and the need for therapy and psychosocial support during the breast cancer journey was highlighted by many participants.

> *"What we need is a therapist. We need therapists to come alongside the care team because what we go through when we're when we're battling something so, so horrific and traumatic, it weighs on our emotions." Participant 001*

This participant spoke about not being offered psychosocial supports and having to advocate to see someone.

> *"I actually had to um had to self-advocate by asking for a social worker, because from what I remember, my mother's journey, she had a social worker that was instrumental in her journey…So I actually self-advocated and I believe, yes, they did they did provide me with a name and phone number. I believe I had a conversation with the person that they directed me to. And I just didn't feel comfortable. I didn't feel like they understood and could relate to me the way that I needed to be related to." Participant 001*

Another participant explained how she did not find her social worker helpful when managing her mental health concerns.

> *"...I didn't feel- I felt like a lot of the um, the options that she was, she was suggesting to reduce my anxiety and stress levels, I was already doing. So I didn't feel like she was providing any additional information. Um she- so for example, like I said, I meditate a lot and that was one of the- that was one of the suggestions that she provided. And you know I mentioned to her, I'm like, "Oh, well yeah, I do that. Like, basically every day I do yoga, I do meditation." And she- yeah, she wasn't really able to come up with a lot of things that I wasn't already doing. " Participant 010*

4.5.6 Mental Health Support for the Family

Participants discussed the need for mental health support for partners and children, not just for patients. For participants that are mothers, support for children was highlighted. One mother discussed the impact of her diagnosis on her daughter's postsecondary education.

> *"It was affecting my child at school. It was affecting her, and I didn't know.... 'Go tell the professor that your mother was diagnosed with breast cancer and you both are going through a rough time and let them re-assess it.' And she says, 'no mom, because this 'C' means cancer. And every time I look on my transcript and see the 'C,' it will remind me of what you went through.'" – Participant 017*

Another participant spoke about her young daughter's anxiety.

> *"She had to grow up quickly. And I tried to spare her from, you know, like taking care of me and that kind of stuff. Um, but, you know, she really did from a young age, have to entertain herself. And be comfortable with being alone, right? ...And then there was a whole pandemic, so we can't pretend that that wouldn't impact as well. Um, you know, for her watching me go through multiple surgeries, uh, she experienced... anxiety, but in her way. Right? So...for the first two surgeries, I couldn't get into my bed. She slept in the living room with me… on the other couch because she would wake up in the night and look to see if my chest was moving, to see if I was breathing. At five years old, that's a lot to carry, but it wakes you up in the middle of the night, right?" Participant 037*

4.6 Body Image and Intimacy Challenges

Participants discussed the impact of treatment on their body image. One participant discussed how she didn't feel that her body after breast cancer treatment lived up to societal standards of beauty.

> *"Because what you feel is that you're not living up to that standard. So as much as I would like for it to change, um there's just way too much like pressure, and like too many images and too many like images of women with breasts, for me to feel like, "OK, well, this is normal" or that "This is OK." Um even though I know that you know those feelings are not good, necessarily. Um the pressure is such that I feel like I'm not living up to that beauty standards." Participant 010*

Several participants discussed not feeling womanly or like themselves during certain parts of their treatment.

> *"I did not feel desirable at all. I feel, I didn't feel pretty." Participant 001*

One participant explained her disappointment with her reconstructive surgery and how her surgeon explained that with her skin complexion it wasn't 'going to look pretty'.

> *"So I did this surgery called a DIEP flap surgery…and it's when they take fat from your stomach to make a breast out of it, and then, you know, they take skin from somewhere else to put it on top. So I'm researching this surgery, and all, all of the... images that pop up on Google is like…all are like white woman, and how it's supposed to look on a white woman. And so I have a little ideas like, 'Oh, this is how it's going to look like. It's going to look great.' And then I went for my surgery, and it's so different than what it looked like…And so I remember, like asking my surgeon, I'm like, 'why do I look like that?' And she's saying, 'you know, because you're from darker… you have like a darker complexion. Um, your skin... tends to be very - like it gets very, very dark when you do like skin transfer or transplant surgery.' So she said 'it's like you know, I probably should have told you, that it's not going to look pretty and that it's just going to be like something to feel good for yourself and your clothes.' But like, you know? But that's not fair because I also want to look at myself and feel beautiful and feel sexy and feel all these things that all these other women get to feel when they get reconstruction. And now I'm just like, you're like, 'OK, this looks really different,' and it's very loud. And it's very... um, I don't want to say disappointing because I'm still grateful. But it's like, close to disappointing, if that makes sense." Participant 019*

The option to breastfeed in the future was important to several participants. This played a role in one participant's surgery decision-making.

> *"But I chose lumpectomy because I, I am so young and I wanted to breastfeed, and I thought that that was probably the best option..." Participant 039*

Another participant, discussing what she would change if she had a magic wand, discussed breastfeeding, which is no longer an option for her. She also expressed her hopes for more breast conserving treatments to be available in the future.

> *"I'll never get to breastfeed again. I can have children, but I'll never get to breastfeed again…the one thing I would wish for is long gone…I'd like to be able to breastfeed uh, without the fear of what happens if it comes back. Um, I would have loved if there was a way to get rid of the cancer without getting rid of my breast. That would have been great…can't give me what I want, but for the next person, can we... treat and cure cancer without slash and burn." Participant 037*

Many participants discussed losing their hair to chemotherapy treatments. However, they varied in their perspectives. Some participants expressed that the hair loss was difficult but part of the journey towards health. Others mentioned the importance of their hair to culture and identity.

> *"I see for women of African ancestry, I think that they equate their hair with beauty. So whenever we're able to throw on like some what we call like a weave or extensions or braids or whatever, that is our... that's our center point of feeling confident as women, as Black women. If we can - if our hair looks good, then we're good [laughs] kind of thing. So I think that's where it stems from. But going through what I went through made me realize that hair or no hair, [laughs] I'm beautiful, you know? Hair or no hair. So I started to embrace - I never I don't believe I ever went outside bald. I don't believe I did that. But I started to walk around the house without, you know, having my wig on or a head tie or something." Participant 001*

Several participants mentioned that they did not mind losing their hair or that it was a small price to pay to be healthy again.

> *"Didn't mind my hair falling out so much. I was OK with that. Got a henna crown. That was nice. " Participant 037*
>
> *"I kind of saw it as like a small price to pay for, you know, just being able to be healthy again. Um, but obviously yeah, it was at first it was like, really, it was a shock, a shock… I don't think it really affected me as much as I thought it would…it grows back, so it's fine." Participant 039*

Some participants mentioned gathering with friends to shave their hair, in a ceremonial style before they lost it to chemotherapy.

> *"We kind of made a party out of it and like had a couple of girlfriends over and they shaved it, and we had champagne, and, you know, it was nice. So yeah, I tried to like, just always kind of stay positive. Got some nice wigs and yeah." Participant 039*

> *"My friends, I had a party to cut my hair because in, in the initial stages um, I felt like, OK. Cancer's going to take a lot from me. But what is something that can be true, right? Cancer can't take my personality unless I, unless I hand it over. So I literally said to myself, you know, I'm going to be me. So what would me do in this situation? I said me would have a party, right? That's um, so I did…we tie-dyed head scarves. And then uh my friends... all took turns cutting my hair. I had 24 inches of dreadlocks, all down my back. I loved my hair. I loved my hair. I don't think I had that - a relationship with my hair until I had dreads. I absolutely adored my hair." Participant 037*

Several participants mentioned being told by friends and family that they looked good bald. A couple of participants also mentioned changes to their hair texture after chemotherapy treatment.

> *"You know what? To be honest with you…Everybody tell me that I - I - I look so good and I look much younger, so I don't know even if the hair grow back, I think I'm going to cut it off again…Yeah, because everybody telling me I look so good and I even look younger than my age...I just glad to know that, you know, who see me said to me, 'Oh, you look so good.' The the the the headless hair look good and it fit you so you know - everybody telling me the same thing, you know that I look good, so I'm glad for that. So I feel good about that, you know? I don't have to be very hot, cover up my hair. You know, I go home and I bring two wig with me to wear and I did not wear one of them." Participant 022*

> *"The good thing about dreads is that I could sew them back on, right? [laughs] Which I didn't do. I still have them. I didn't sew them back on, but um, because my hair texture is completely different from what it was originally." Participant 037*

> *"Um what's interesting actually, is it grew back the opposite texture of what it was before, which was kind of like... Yeah, which was kind of cool." Participant 039*

One participant spoke about her experiences with hair loss being invalidated because she wore the hijab. She also mentioned the experience of another Black cancer patient who felt that her experience with hair loss was not taken seriously.

> *"For me, specifically, like um being a hijabi woman or Black Muslim woman going through cancer, is pretty challenging within itself because people oftentimes don't believe that you're sick because you don't look sick. Um, one of the main uh... giveaways of being a cancer patient is no hair. And so when I have things like makeup and a hijab wrapped around me, people oftentimes um... either didn't know I was sick or wouldn't take my*

> *illness seriously, or wouldn't take the trauma of losing hair and you know, feeling less womanly, I guess you can say um... seriously." Participant 019*

> *"...just not feeling seen or heard. Um, in terms of Black women, specifically out of my two other friends that I met at camp were um Black teens that dealt with cancer. One of them was a girl um, and me and her, we would just talk about how um.. like it was super traumatic to lose our hair and people just didn't take it seriously. Um, and so, like for my friend, she was saying how like... because she would always wear protective styles and things like that for her hair, um, they just, like, never really disregarded her, like she just felt as though that like, 'oh, you know, like, you already look so good with the kinds of hair that you have now. Like, I'm sure it wouldn't be a problem for you like to transition to wigs or anything like that,' as if it was like easy, breezy, beautiful covergirl. Like, she was like, 'No, this is still really hard for me.'" Participant 019*

Many participants spoke about feeling invisible, not feeling seen or heard in breast cancer spaces, and the importance of self-advocacy.

> *"...you really have to advocate for yourself. I feel like that's such a common thread among like young women I've talked to, um, that they also didn't feel seen or heard, especially Black women. Yeah, I know this is a reality. Like it can happen. But also, like I like to say, it's like - it's part of my story, but it's not my whole story, right? Like I don't want this to define like the rest of my life. Um, but I also want to advocate for others to know that like, this can happen and you need to advocate for yourself." Participant 030*

> *"...just like speaking to my friend, like we had- I think like we had similar experiences of just like feeling invisible. So just feeling seen and feeling heard, you know, that is extremely important. It does a lot for your mental health, um you know, because I'm like, "OK, maybe it's me", but then you speak to someone else and you realize, "Oh, no, no, it's not me. It's actually an issue that multiple people are experiencing who look like me". Participant 010*

Participants spoke about body image and the effects of physical changes on intimacy. Some were uncomfortable discussing their experiences with intimacy during their journeys. However, some participants mentioned that intimacy with their partners was affected during their treatment.

> *"It was kind of nonexistent during the - during the process because I had so many things going on hormonally. And just like physically, I felt really, you know, not myself. I just didn't feel like myself." Participant 039*

Some participants discussed changes to their sexual health, such as vaginal dryness and changes to sex drive. Some participants expressed that their sexual health concerns were not address at all or in some cases inadequately by healthcare providers. Many participants were not in relationships and shared their concerns and anxieties about dating and discussing their experiences with breast cancer surgery and reconstruction with future partners.

> *"At first it looked like really... Scary. Um, but my reconstructive surgeon did an amazing job, so now, honestly, I like, I think they look great. Um, aside from not having nipples, which obviously is like going to be a shock to a new partner, but I think aside from that, like, I'm really happy with the results." Participant 039*

4.7 Importance of Fertility Preservation

For participants who were diagnosed during their childbearing years, fertility was an important consideration. Participants discussed having conversations about fertility preservation with their health care providers before starting chemotherapy. Many discussed the importance of having a family or growing their family in the future. One participant who was not offered fertility preservation discussed the impact of this on her life.

The importance of fertility preservation is highlighted by one participant’s explanation that the very first thing she was concerned about when she got her diagnosis was her fertility. For this participant, freezing her eggs provided her with options to have children in the future.

> *“I did freeze some eggs. So I'm excited for that because I wanted options. The very first thing that when they told me the diagnosis, I was like, 'Oh my God,' I've always wanted kids and I was like, 'What's going to happen here?' And that's- they put me- they gave me some relief in that sense because that was my big concern...I did all of that…before chemo...I got to store some eggs, so it's good." Participant 043*

Several participants mentioned wanting a family or the option of having children in the future.

> *"...I would want a family like for sure, that's kind of my main thing. "…the main thing for me is like the children thing, because that was - that was the hardest part. Like, I've always wanted to have children, and that was the year - the year of my diagnosis was the year I was planning to have a child. " Participant 039*

> *"…when the medical oncologist said that chemo affects fertility, that was harder news than cancerous cells were found…I was like bawling in the hospital… And oh how I bargained and I tried to talk to the doctors to see if we could have the baby first and then come back and, you know, all of these different things. Um, and the surgical oncologist…looked at me as said, 'a pregnancy will kill you because of the type of cancer you have.' He said, 'if you walk out of here now, and get pregnant, there will be nothing I can do for you.' …But for me and my husband, you know? That's been a part of the uh... of the hope that sustained us, you know?... Yeah, I, I would have been... distraught. I would be willing to venture to say I would have had a complete mental breakdown if I had found out afterwards, that fertility preservation was an option that I hadn't been offered, I think I would have gone ballistic, right?" Participant 037*

Participants described the rush of making decisions about fertility before starting chemotherapy and how they wish they had more time.

> *"I feel it was rushed. I think it was rushed because of the whole chemo thing. I kind of wish I had more time and I really wish I had more time to actually detox from that… And I kind of wish I had more time to kind of flush that out of my system, then do chemo…We are here, where we're at, and I'm over it, but it, it was rushed. It was boom, boom, boom. I wish I had more time." Participant 043*

> *"I had to have my eggs frozen…I think it was right before I started chemo. So that- the, the process leading up to chemo it was- everything just went very, very quickly. Um I had the surgery and then I had to immediately get fertility drugs. And then I had to have um my eggs retrieved, which was a process in and of itself." Participant 010*

Some participants also explained their fertility preservation decision-making process. One participant chose to freeze eggs rather than embryos because she and her partner were not ready to make that decision at that point in time.

> *"...I just wanted to freeze eggs because my boyfriend is like meh and I'm OK with that. I still wanted the option to freeze my eggs. So that at least I have it stored…I chose egg freezing because I just needed that resear- reassurance." Participant 043*

Another participant expressed regret over choosing to freeze embryos with her then husband, even though the decision felt the best at the time.

> *" But now that I'm no longer with my husband, those embryos are not of any use. So it kind of - it's definitely devastating that I went through that whole process for nothing…I*

> *should have frozen the eggs. But I mean, I was married, so I didn't think that like - I thought it would be kind of weird when the question was asked, if I went with eggs over embryos, when embryos have a higher survival rate and like it would have - It was going to accelerate the process. Um, so it was the only option that seemed... Like, reasonable at the time, but obviously looking back, I feel like I made a mistake." Participant 039*

This participant also expressed worries about the risks of stopping hormone therapy to conceive.

> *"My oncologist said that I am able to come off the drug after two years of being on it in order to have a child, but then I would have to immediately go back on it…that's the main thing that kind of like haunts me every day is like, what's you know, how am I going to go about this? And if I do come off the drug, it's kind of putting my health at risk at the same time, right? Because that's kind of what's protecting me right now from the cancer coming back." Participant 039*

One participant spoke about her experience not being offered the opportunity to preserve her fertility. She explained the impact of this on her life.

> *"I had no discussions about options at all, even if it was for the future, even if they told me your fertility is going to be impacted, they still - like having that discussion still didn't prompt them to talk about options, which I felt like was super unfair. And in regards to how I feel about that now, I actually fear more for the fact that I won't be able to have children, more over, the fact that I would ever relapse in my cancer. That's how worrisome and how, like, how much I favour um being able to have children and being able to build a legacy versus getting sick again. Like for some people, I know there's a hierarchy, but like, I don't like the fact that other people were, um, you know, changing that, that hierarchy for me, and, you know, assuming that as long as I'm alive and I'm okay, it's okay if I don't have children. Like, I would very much rather still want the option to be able to have children because whatever happens in the future is whatever happens in the future, and I'll be able to deal with it in terms of illness. But um, fertility is like something that was super overlooked, um, and it's something that I - like out of that whole experience, I think that's the number one thing that angers me the most." Participant 019*

This participant mentioned that she met other young Black cancer patients who also did not have the opportunity for fertility preservation.

> *"…Um, so it was really odd. [Name of Hospital 1] has this cancer camp. And like, in that cancer camp, there was only like three Black people in like a hundred and fifty white teens. And like, so I went to this cancer camp and everybody at this camp was telling me how they got the option to get their eggs frozen or like, you know, they got to talk about like just different kinds of fertility things and um, me and you know, my other Black folks,*

> *we all looked at each other and we're like, we were not given any option, any talk about fertility…because it was too coincidental um for me and my friends to all collectively go through that experience. Um, we were just listening to all these other um teens at the camp being like, 'no, like they didn't tell you?' and we were just like, 'No.' And some of us had the same doctors." Participant 019*

She explained that she felt that her healthcare team's decision not to bring up fertility preservation may have had to do with her financial situation at the time.

> *"...I definitely think it does have to do with finances...So I can only imagine, you know, them thinking like, 'well, fertility. Oh, let's not bring that up right now. Like, maybe she's struggling with cabs [transportation] at this point in time. Maybe we don't need to, to bring up fertility.' ... That was super hurtful and an opportunity that they took away from me." Participant 019*

There were also financial implications of fertility preservation for one participant whose medication was not covered. She had to rely on financial support from her social network.

> *"Um so the appointments were covered because I was a cancer patient… but all the medication was not. So I actually a friend of mine, she's so sweet, but she made a go fund me and so I had support from that in the costs of uh the fertility…." Participant 039*

Another participant mentioned the cost of storage fees for her frozen eggs. She mentioned that she felt fortunate that fertility preservation was possible for her, as she knew of other women who were not able to.

> *"...And um now they're at [Name of Hospital] and I'm paying three hundred dollars in storage fees each year (laughs) each year to keep them there. So yes, that was part of the conversation, which was good because I did see a few women in a few of the Facebook groups where for some reason they weren't able to um have their eggs retrieved before they started treatment. So you know I did feel very fortunate, even though I'm not sure that I want to eventually have children." Participant 010*

Another participant was directed by one of her healthcare providers to a charity that provided financial support. She mentioned her disappointment with the provincial insurance plan only covering one round of invitro fertilization (IVF) and discussed the financial implications of freezing her embryos, rather than freezing eggs.

> *"Saving grace was that the... first medical oncologist shared with us a charity that um helps you to cover the cost of fertility preservation…You know, the bill came in, it was like $23,000.00 and we were only required to pay like $300." Participant 037*
>
> *"Except for OHIP only paying for one round. That part they can fix." Participant 037*
>
> *"...first of all, OHIP covers freezing eggs, but not embryos, although medically you have a higher success rate freezing embryos than eggs…and then so few insurance companies touch IVF…I mean, there are so many variables, right? If the um... if the doctor had an offer to request compassionate meds, if the pharmaceutical companies hadn't approved the offer for um, uh, for compassionate meds, you know, if the charity hadn't approved the application to um... they were refunding, you had to pay for it and they refunded about $1800. I can't remember. Your first year of freezing or something like that. You know? Um, if, if any one of these pieces fell through, we would - we had no shot you know?" Participant 037*

4.8 Financial Burden

Many participants noted the important role that finances played in their journey. This included out-of-pocket costs. Participants mentioned relying financially on personal savings, as well as family and friends. Several participants mentioned the cost of medication from the pharmacy during chemotherapy treatment.

One participant mentioned the financial stress of having to pay for her prescription medication, as her pharmacist would not wait for the government insurance. This left her owing money for rent and relying on her family and friends financially.

> *"So I had to be paying out of pocket…I had to pay for a chemo pill before chemo and then that was like almost $200…Every week I'm trying to figure out if it comes through. I have stress- like, 'OK, would I be able to do my chemo if they don't, if they - if it didn't go through,' right?...I'm still in arrears from my rent because of all of that." Participant 008*

Another participant wished she was told about the costs she would incur earlier, as she was shocked by her out-of-pocket costs that were later reimbursed.

> *"...I think like more transparency, because um, I - initially I wasn't really told about all the costs that were going to accrue. Like, I kind of just was like, 'Oh, we have free health care system,' but during the process of uh treatment, it's actually quite expensive…I didn't realize, you know that every time, every time I went to chemo, I would need to the following day, uh take an injection, which was $1500…I was shocked when my first day of chemo when they sent me to the pharmacy and she told me, you know, I owed a thousand five hundred dollars…I broke down crying." Participant 039*

Several participants discussed the challenges of applying for the provincial drug program. For one participant enrollment in the program resulted in delaying her chemotherapy treatment.

> *"…then I had to apply for Trillium…So I had to start chemo later, basically. It prolonged the process because I wasn't able to get the shot at the time. So yeah, I would just say more transparency about like the costs and uh and just like what's involved, you know, moving forward." Participant 039*

Financial costs also included medical devices. One participant mentioned that she had to pay out of pocket for her lymphedema sleeve, which was not covered by her insurance.

> *"...I got the sleeve, had to pay for it. No insurance covers it sleeve." Participant 037*

Participants also mentioned the cost of food, especially fresh produce, was a significant financial factor, as well as some health service costs, such as seeing a naturopathic doctor, that were not covered by provincial insurance.

> *"…so that financial piece, I know I'm going to have to figure out at some point. How to make things stretch and manage because food is not cheap, because I'm doing organic food. That's not cheap. Plus paying rent. I don't own right now. Um, so all of these things are going to definitely add up." Participant 043*
>
> *"I will say seeing all of these health professionals, it adds up and it's not something that government is paying for and it's not- um I'm not upset about that, because I think I need to do what I need to do and not rely on the government to give me anything because if I waited for the government, I'd be dead, to be honest with you." Participant 043*

The majority of participants were on disability leave from their employment, whether short or long-term. Several participants mentioned that the switch from short-term to long-term disability had or will have a significant impact on their finances, through wage loss or income reduction.

> *"…it's a little bit difficult financially now because I'm on long term disability…So I was on short term disability for six months. Well, I practically got most of my pay, which is fantastic. But now I'm on long term disability, so I actually only get about 50 to 60 percent of my pay. It's better than nothing, don't get me wrong, but it doesn't pay all my bills. And, you know, because I said I went through a separation…we sold our house and there are lots of issues that were going on… I didn't get a lot of money from it…So I moved to a new place and um I'm literally starting again…it's been it's been quite tough, um... to start dealing with this, I'm dealing with the cancer and the financial expenses… I did save some money from the sale of the house because I knew about the cancer diagnosis…And now that's what I'm using to cover my top up, to cover all my expenses." Participant 042*

> *"I have a buffer of six months where I'm on the short-term disability. And then from there it turns into long term, and that's when I'm going to see the dip. So, I do need to plan for what that looks like...Because, yes, finances definitely plays a role, and um I have been mindful thus far. But it does add up." Participant 043*

Some participants spoke about childcare and its financial implications.

> *"Well, certainly childcare. And you don't have to be sick for that to be a challenge…once I knew I wasn't going to be working, so during chemo, we didn't pay for before and after school because I knew how much time I would have left and that I wouldn't be working and stuff. Um... we connected with another non-profit that provided free childcare for a few hours, which was nice, but I think the, the greatest benefit of that organization was that they're led by child life specialists. And so the, um, individuals who volunteered to support the children are trained to handle difficult conversations should they arise. My daughter was four. She just wanted to play. You know? That was hard not being able to play or having to tell her to wait three, four or five days before I could again." Participant 037*

Additionally, transportation costs, such as the cost of parking, was highlighted as a significant cost for some participants. This was a financial burden for participants who mentioned multiple medical appointments and the daily visits to the hospital required for radiation therapy.

> *"…I had to pay an extra $20 of parking, which for your salary is nothing but for me, somebody who has not worked since March, 20 dollars is a lot." Participant 007*

4.9 Lack of Representation

Many participants spoke about the lack of images of Black women with breast cancer or clinical images of the disease on Black skin. This included the lack of Black women in the information packages provided to participants upon diagnosis, lack of clinical images of the effects of radiation therapy on Black patients, lack of skin shade representation on prosthetics or lymphedema sleeves, and lack of wigs with afro-textured hair in hospital salons.

> *"…one of the things that struck me was that there were just no images.… my body wasn't present, so it was kind of difficult to like even just imagine what my body's going to look like post-mastectomy and post-plastic surgery because there were, there were just no images of that." – Participant 010*

> *"... when I received my care package, when I saw the oncologist… none of them really resonated with me. There were none with - with colored faces on it… the literature really wasn't representative of our heritage. You know, the heritage that I grew up with. And um you know, for - for me, being diagnosed with triple negative breast cancer that is very prevalent in the Black community, the African - African ancestries, the sense of West, the West Indian culture..." Participant 001*

> *"Similarly… there is a display of lymphedema sleeves and they're all in nude, but they're not my nude, like nothing matches me. So it just- I felt pretty much invisible." – Participant 010*

Participants spoke about feeling invisible and invalidated by not seeing representation of themselves in breast cancer spaces. Some shared their experiences of feeling othered in breast cancer support groups. The experience of not seeing other Black women in clinics or support groups made some participants feel hypervisible and like the only Black women with breast cancer.

> *"...I do remember doing um a support group with a, with two social workers um for teens with cancer. And like um, I was just in a room with people who like none of them were people of colour, nor were the invigilators um or the social workers. Um, and the - even the students that they would take on from placement, um, were not even people of colour so [laughs]. Well, I remember the one thought that I had was like, feeling like, 'Damn, I*

> *feel like Black people don't get cancer.' Like, I just feel like, I'm very um, I felt very "other" in, in that room, to be honest." Participant 019*
>
> *"It's just an overwhelming um experience and I don't see a lot of people my skin, and maybe they're there on the days that I'm not there, but just to see young, younger Black women during this time, I don't see it. " Participant 043*
>
> *"I never saw another Black female throughout my entire uh, throughout my all, my treatment, I never saw, actually... Yeah, everyone was... white that I would see, uh at the breast centre at [Name of Hospital 1]." Participant 039*
>
> *"They were always very open to receive me, but it was... 'OK. This is the only Black woman in the world,' so it was like a 'ooh who's that?' Something new for them." – Participant 018*
>
> *"…when I got the diagnosis, I'm like, 'I'm the only one.'…I don't know any Black women that have breast cancer… What's going on?"- Participant 021*

Several participants mentioned the lack of psychosocial supports specifically for Black women and how they feel they would benefit from being around other Black women going through similar experiences.

> *"...I thought I found something that was tailored towards Black women. But no, there are, there are, no, none… So if there was like a large group of, a group of us for sure, that would have been extremely helpful." Participant 010*
>
> *"...it would be cool if there was like a support group for Black women. Just putting it out there, there might be an I don't know about it yet here in Toronto, but, yeah. Just to share stories to share, especially about, again, the cultural food piece of things. How have they adapted? Right? I'd be curious to know about things of that nature." Participant 043*

Additionally, many participants expressed the need for racially concordant care and how they believed being understood by their healthcare providers would improve their health outcomes by allowing them to feel safe, seen, and heard.

> *"...I would probably like to see more Black women doctors or just more Black doctors in general within the process. I think that would help me feel more safe, more heard. My doctors were great. I'm not disparaging them in any way, but um I think that's one thing that I would like to see more of. Or more you know women of color doctors if you will (laughs), so I'll take that as well (laughs)." Participant 010*

4.10 Mistrust of the Healthcare System

Participants spoke about their lack of trust in the healthcare system and in healthcare providers as a result of direct experiences with inadequate care or personal beliefs.

> *"I think uh, I now have a severe lack of trust of doctors. I think there is um... a disconnect between Black women and doctors. Um, primarily like within all aspects, but more specifically with cancer screenings and awareness and diagnosis. I think there's a huge disconnect there. Um, I felt like I did not trust my doctor at all. Um and it's through that experience where I still don't trust doctors. So um, yeah. I think there's a huge disconnect there, for sure." Participant 019*

One participant explained how she could not say she trusted the Canadian healthcare system due to several reasons, including regional differences in care. She also wondered how women who do not speak English as a first language are able to manage.

> *"I go with the Americans on this trust, but verify, right? Um...trust. Trust is a heavy word. Um, there's a lot that wouldn't have happened without my voice. Right? There's a lot that wouldn't have happened... without things that seem coincidental. So systematically speaking... No. Understanding that my care could be vastly different across municipalities, that breaks trust. Across regions, worse, across provinces, worse. Um... no - thinking about my friends who don't speak English as the first language. I wonder. How they would get what they need. I barely know these words in English. You know. Yes. There are translation services and all these things are provided, but that's not another person in the room. When you you're having very emotional conversations. So trust is a is is a much heavier word that I can safely use. Am I grateful for the Canadian health care system? I'm grateful. " Participant 037*

One participant's mistrust of the healthcare system had to do with her experience with medication that was supposed to shrink her tumor and her physicians finding out six months later that the tumour has doubled in size.

> *"They were - they were treating it. They were giving me two different kind - kind of tablets…and I take those tablets for six months because they were trying to reduce the lump because of where it is. They say it's a delicate spot…And when they check it six months instead of reduced, it was like two times the size…So they take me off the tablet for two weeks and then they did this surgery. But they telled me not to worry…To know, I'm taking those tablets and it wasn't doing anything." Participant 022*

One participant spoke about having trust initially but that it eroded over time as a result of her experiences.

> *"...I think- when I initially went in, I had trust, but it slowly started to erode. And that's just because I felt like, "OK, no one's thinking of me". And I think, you know, even in the beginning of my treatment, like I read a statistic about Black women, the mortality rate being a lot higher for Black women. And that was never even mentioned at any point during my treatment and any type of additional information as to why that is, right? So, um I think- while initially I had trust, it did slowly start to erode along the way." Participant 010*

One participant spoke about leveraging her mother's whiteness to get answers to her questions.

> *"Sometimes I would feel like when I was asking questions at the hospital, my - I was getting a watered down, dumbed down version of - of answers or that...I was told, you know, 'you don't have to worry about this now. We can talk about this at another appointment.' And so I started bringing my mom to my appointments. My mom is a retired RN and speaks medical jargon [laughs] very well. My mom is white and so I just felt that bringing her to the appointments - to my appointments, my questions that I wanted answered would get answered because she was there." – Participant 004*

One participant spoke of her lack of trust in the healthcare system as a health professional herself.

> *"No. I hate to say it. Because I worked in it. Something's got to change. We've got to be having more clinics open, available for people for screening and getting the treatment they need faster than waiting. And I don't care again if another pandemic or if something else happens, nobody should have to wait for treatment, ever. It should be available. To everybody, not just the paid system. To everyone. We are so backwards here. We have a lot to learn. We have a lot to learn." Participant 043*

Some participants also qualified their trust by comparing the treatment they received to the experience they might have had in their home country.

> *"Well, I'm not going to say I, I, I trusted them a hundred percent. I am very glad to know that I am here…back home in Jamaica, the help that I get here, I wouldn't be getting um, that help back home. " Participant 022*

One participant explained how her cancer diagnosis was delivered to her in an unexpected and unprofessional manner, while her child was present, and she had no one there to support her. This participant later experienced a panic attack.

> *"…I was supposed to meet with the doctor…a few days before I was supposed to have the appointment that I was prepared for, um, I went to my... family doctor's office to get a document signed. She wasn't in and then asked another doctor who was very new, um, to sign it instead. Um, and this doctor looked at my... results and then decided that it would fall to her to deliver this news. Um, so I had no relationship with her. You know, I'm going through this process with another family doctor I've been with at that time, maybe three or four years, you know? Um, and my four-year-old is in the room, and I'm not with my family." Participant 037*

One participant spoke about feeling like she was rushed out of the hospital after her surgery.

> *"I have this surgery and…I didn't even wake up good. And they - they - they take me out of the bed and tell my daughter to come and get me and they carry me in a wheelchair right outside…and send me home. Yeah, I didn't even wake up when they sent me home." Participant 022*

Several participants discussed dismissal of their concerns by healthcare providers throughout their journeys. One participant discussed the dismissal of her symptoms by multiple health care providers until she was finally diagnosed.

> *"...she [provider] was so passive, and it wasn't, it wasn't the first time. Me and my mom, we have this inkling that I've low key had that... um, that tumour in me since I was in 10th grade, I was in - I graduated high school when I went to [Name of Hospital 1], when I got sick but... Me and mom were like, I could have had this tumor for a very long time and it was just dormant and nobody wanted to talk about it. And I went to multiple doctors and all they would do is breast examinations and be like, 'You're fine, you're OK.' And these were all... white doctors. [laughs] None of them were people of colour at all. " Participant 019*

Other participants mentioned the dismissal of their symptoms and inadequate pain management.

> *"…I get a lot of body pain and I keep telling them that the um, medication that they give me is not helping… there's one other female that I connected with from the clinic… she got a different medication from me and it helped. And she's not - she's not Black right? And even when I told them that this is what they gave the same person, they're like, all,*

> *'just keep this one. Just use this one.' And I'm like, 'but it's not working. I'm in pain... I'm just over it. I just have to just bear the pain where I know that I'm going to be in pain." – Participant 008*

> *"...I think it was dismissed to a certain extent. Yeah, I think it was dismissed. Um, I don't know - I don't know why. I mean, kind of like - I'm not, I'm not the kind of person that, you know cries that I'm in pain. It was dismissed. As I said, I went to E.R.. The first time I went to E.R., I wasn't going because I was in a lot of pain. So the pain coming almost like got worse later. So the first I went to, it was because of the bleeding, yeah? Um, but and then the second time I went to the I was in a lot of pain." Participant 042*

Some participants discussed the lack of accountability of healthcare providers who made them feel unseen and unheard.

> *"And then the people who are supposed to be saving your life, can't even check your file to see if you're fucking vaccinated, like what? So what else are you going to miss? If you couldn't check that, what else are you going to miss in my care? And then, who do I tell? Like, there's an email for patient relations. But does that like go anywhere? Does something to happen? Like if somebody's going to read through my email of complaints and actually go talk with that doctor ...So like a support person along the way, somebody to check in on you and somebody to tattletale, like, we're - because like these doctors can walk around and who are they accountable to? Who are you accountable to? You just do this shit to me and a hundred other patients and nobody knows? No. There need to be somebody who we can tell because then maybe the doctors have it in the back of their mind. Like, if I'm rude to this patient, they can report me. If they don't have that, they can do anything to us. As a patient, like, what am I going to do? Am I going to yell at a doctor that's supposed to be saving my life? No. I'm just going to shut up and go in my car and cry." Participant 007*

Beliefs about inequitable treatment for Black women and the need to improve the care that Black women receive was expressed by several participants. One participant discussed feelings that Black women don't get the same treatment as other patients.

> *"The only thing, the only thing I know, I don't think Black women get the same treatment as - as white. I think they get less look after…Yeah, because because they are Black, because my younger sister died from breast cancer and she did not get the look or started treatment she should get. And I just believe it because she was Black….but they didn't look after her properly. She didn't get the proper treatment…She - they didn't um... they didn't actually do um, um... radiation. And uh... they give her different - different - she get about six different kind of... chemo treatment. None of them didn't work." Participant 022*

Other participants expressed their wish for more equitable care for Black women.

> *"…for Black women going through breast cancer, just that everybody's supported and feels that they're given the same treatment and attention…sometimes I felt like a disconnect, like maybe it was race related. I don't think at the time that crossed my mind, but it could have been. So I just, you know, I would want everyone to feel like they had support from their health care team as well as those around them…'cause that really changes your experience with treatment." Participant 039*

> *"I would say, um, more equitable health care, for sure. If I had a magic wand, I would use it for that." Participant 019*

Chapter 5

Discussion and Conclusion

5.1 Importance of Social Support and Community

Family, friends, and community were clearly an important source of social support for Black women with breast cancer. In general, social support is associated with positive adaptation (Dukes & Holahan, 2003) and improved survival for women with breast cancer (Maunsell et al., 1995). Some participants had family members and friends fly in from abroad to help them during active treatment. Extended social networks and greater social support is associated with improved quality of life for women after a breast cancer diagnosis (Kroenke et al., 2013).

However, some participants had small social support networks and others chose to limit their social support for reasons such as not wanting to burden loved ones or to protect their own peace. Several participants also expressed concern about Black women who don't have as much social support and how they are able to manage. This concern is valid, as women with breast cancer who are socially isolated have a higher risk of mortality, likely due to lack of caregiving support from family and friends (Kroenke et al., 2006).

Participants also discussed the impact of their diagnosis on their relationships with friends and partners. Intimate partner relationships were mentioned by some as very supportive, and others were especially challenging leaving the woman will little or no emotional support. The implications of mental health and psychosocial support for Black women with breast cancer are discussed in section 5.4.

5.2 Importance of Faith and Spirituality

Many participants spoke about the importance of faith and their spirituality in coping with their illness. For some this was participation in organized religion through church attendance, participation in faith-based community groups, or personal spiritual beliefs. Research supports the role of religion in helping women with breast cancer to cope (Johnson & Spilka, 1991). In the US, spirituality is an important factor of not only African American women's coping but reframing of their illness experiences as well (Sheppard et al., 2011). The significant role that spirituality and religion plays in the cancer experiences of Black people has been explore by studies in the US (Bai et al., 2018; Potts, 1996; Schulz et al., 2008; E. J. Taylor, 2001; Underwood & Powell, 2006) and in the UK (Koffman et al., 2008). More specifically, the importance of spirituality for Black women with breast cancer has also been explored by researchers in the US (Leak et al., 2008; Samuel et al., 2016; Tate, 2011). Spirituality appears to be the main coping mechanism for African American women during all phases of their breast cancer journey (Tate, 2011) and is associated with improved quality of life (Leak et al., 2008). Quality of life is significantly related to spiritual wellbeing for African American breast cancer patients (Morgan et al., 2006).

Participants also spoke about the importance of faith communities for providing both emotional support through prayer, as well as practical support such as providing meals and transportation. The role of emotional and practical social support provided by church communities on physical and psychological health has similarly been described by Black Caribbean cancer patients in the UK (Koffman et al., 2008).

Participants also spoke about their experiences, connecting with God, the importance of prayer, and finding purpose in their journeys. These experiences of introspection and gaining purpose or new perspectives on life echo the spiritual experiences of African Americans with cancer in US studies (Potts, 1996; Schulz et al., 2008). For African American breast cancer survivors and their caregivers, religion and spirituality have been found to play a significant role in survivorship through the provision of guidance and facilitating recovery (Sterba et al., 2014). Additionally, faith-based breast cancer education programs have been used to raise awareness about early detection of breast cancer and show promise in improving screening utilization for African American women (Darnell et al., 2006; Hou & Cao, 2017).

Only one participant identified as Muslim and spoke about the role of her Islamic faith on her cancer journey. Her beliefs of illness as a test from God and an opportunity for the expiation of sins differ significantly from the other participants' predominantly Christian beliefs. Her description of her community grieving her while she was still alive, indicates a complexity of social support for certain Black women. The role of spirituality for Black Muslim cancer or breast cancer patients seems to be largely unexplored in the literature, as most studies from the US focus on the spirituality of a largely Christian African American population. Further research can address this gap by exploring the experiences of Black Muslim women with breast cancer and the role of faith and spirituality.

Recognizing the importance of spirituality for Black women with breast cancer, US research suggests that there should be consideration for the role of spirituality in cancer screening (Underwood & Powell, 2006), breast cancer treatment delivery, and that interventions should be peer and community based, as well as culturally and spiritually consonant (Sheppard et al., 2018; Tate, 2011; Yan et al., 2019). This is consistent with participant views in this study and underscores the importance of cancer support services provided by organizations such as The Olive Branch of Hope (TOBOH), which offers faith-based support and holds events at community churches. However, it also highlights the need for diversity in services provided, to support Black women from other minority faith groups.

However, faith, spirituality, or religion was not important to every participant. One participant clearly stated that faith and spirituality was not an important factor in her journey. Another participant's spiritual practices involved meditation rather than prayer or religious practices. This suggests healthcare practitioners need to consider the nuances of spirituality for Black women with breast cancer, and not to assume or generalize that it is important for every Black woman.

5.3 Cultural Considerations

Participants spoke about taboo nature of cancer in their communities, the belief that a cancer diagnosis is a death sentence, and fear of breast cancer screening. Many participants felt that sharing their experiences through this research, on social media, and through breast cancer campaigns might break taboos and help other Black women.

Several participants expressed that breast cancer information that took into consideration their racial and cultural identities was lacking. They included calls for race-based breast cancer data and a critique of colourblind policies in Canada. In Canada, advocates have called for provincial mandated race-based data collection to have an accurate picture of racial health disparities, rather than current voluntary practices (Dayo et al., 2023).

Black women in Toronto are not monolithic and their cultural experiences differ. Participants' experiences highlighted the importance of community and the need for care that meaningfully addressed culture and intersecting identities. This is in line with calls for Afrocentric approaches to healthcare in Canada, approaches that are grounded in values and worldviews of Black people of African descent (Gebremikael et al., 2022). Healthcare providers and care teams need to acknowledge the cultural identities of Black women with breast cancer and to make sure interactions, information delivery, and programming is culturally safe and appropriate.

5.4 Mental Health and Psychosocial Support

Participants' experiences of anxiety, fear of recurrence, loneliness highlight their unmet mental health concerns. This has significant implications for cancer support programming and planning. Compared to older, white, breast-cancer survivors, young Black breast cancer survivors in the US experience higher levels of fear of dying, have more unmet supportive care needs, experience more financial distress, and have lower functional wellbeing (Samuel et al., 2016). While little is known in the Canadian context, Black women with breast cancer in the US who have higher levels of medical mistrust experience more anxiety and depression (Sheppard et al., 2014). This is also more likely to be the case for younger Black women with breast cancer (Sheppard et al., 2014).

Although many participants mentioned that a social worker was part of their care team, this was not the case for all. One participant's experience of self-advocating to get psychosocial support indicates there is a need to systematically offer services to ensure that no one falls through the cracks. The psychosocial support offered was not always adequate. Participants mentioned not feeling understood or finding their social worker helpful. Participants expressed their need for a therapist that understood them, implying the need for race-concordant care or training that allows therapists to understand and address participants' cultural and spiritual identities.

Loneliness was a significant part of many participants' journeys. Participants expressed their wishes to know other women with similar experiences. Available cancer support groups were lacking for many who felt unseen, unrepresented, and in one case silenced in these groups where they didn't see participants who looked like themselves. Some participants mentioned not knowing other Black women with breast cancer or of Black-specific cancer support groups. Other participants wished they had known about TOBOH when they were going through their own active treatment. There is a clear unmet need for culturally safe, representative, and competent mental health and cancer peer support for Black women with breast cancer in Canada. Given the prevalence of mental health concerns and disparities in diagnosis and treatment for Black communities in Canada at large, this unmet need is even more concerning.

Several participants spoke about the need for psychosocial support not just for themselves but for their partners and children. A finding that is supported by an earlier study of diverse young women with breast cancer in North America found an unmet need for support for family (Ruddy et al., 2015). Participants spoke about the emotional toll of their journey on the mental health of their young and adult children, as well as the challenges with their partners. Psychosocial support planning for breast cancer patients need to consider the importance of support for the whole family and its effects on wellbeing of Black women with breast cancer.

5.5 Body Image and Intimacy Challenges

Participants spoke about the importance of hair to their identity, challenges of hair loss during treatment, and embracing baldness and new hair textures. Hair loss was devastating to some participants while for others the loss of eyebrows was the most challenging. For some participants of reproductive age, wanting the option to breastfeed in the future played a role in their treatment decision-making.

Many participants discussed challenges accepting physical changes to their bodies and at times not feeling beautiful or womanly. One young Black participant was told by her surgeon that her reconstruction was not going to look pretty due to hyperpigmentation. Insensitive and unprofessional communication style aside, the surgeon's comments highlight a lack of care for her patient's body image concerns and of clear relatable information.

Participants discussed the effects of physical changes on sexual health and intimacy. Some felt ill prepared for the changes they were experiencing, such as low sex drive. This finding aligns with a study of racially diverse breast cancer survivors in the US, regarding sexual health. Their findings included that survivors had to adapt to trauma of breast cancer treatment, navigate complicated discussions about sex with partners or potential partners, and negotiate intimacy without sex with partners (Tat et al., 2018). These authors concluded that sexual health concerns are an unmet need for many breast cancer survivors. Healthcare providers need to address the unmet sexual health needs of Black women with breast cancer during treatment and into survivorship.

Participants' body image concerns were also related to anxieties about dating and future relationships. A finding that is supported by a study of diverse young women with breast cancer in US and Canada, they found an unmet need for more information about navigating current and future romantic relationships after cancer treatment (Ruddy et al., 2015).

5.6 Importance of Fertility Preservation

Many participants of reproductive age expressed the importance of fertility preservation, their wishes to grow their families, or to have the option in the future. Cytotoxic chemotherapy and hormone therapy, often used in breast cancer treatment, decreases women's reproductive function (De Pedro et al., 2015). Patients undergoing these treatments should be given counselling about their fertility preservation options (American Society for Reproductive Medicine, 2019). As Black women may be getting breast cancer at younger ages (Bowen et al., 2008), fertility considerations for Black women receiving gonadotoxic therapy are even more significant.

Understanding the sexual and reproductive health of racialized communities requires an examination of oppressive colonial policies and systemic racism (Coen-Sanchez et al., 2022). For Black women, this is arguably even more important in light of horrific medical experimentation on Black women. Dr. J Marion Sims, viewed as the father of modern surgical gynaecology, carried out experimental operations on enslaved Black women in mid-19th century Alabama (Wall, 2006). Dr. Francois-Marie Prevost pioneered the caesarian section surgery through experimentation on enslaved Black women in Louisiana (Cooper Owens, 2017). The exploitation of Henrietta Lacks (Skloot, 2010) and the mistreatment of Sarah Baartman (Gordon-Chipembere, 2011) also have lasting legacies. While many of these examples are from the US, Canada has its own legacy of reproductive injustice against racialized women. In the late 1960s to 1970s, eugenics policies, such as the Sexual Sterilization Acts, led to the forced sterilization of hundreds of Indigenous women (Leason, 2021). The legacy of this history means that Black women with breast cancer need support and information to decide on fertility preservation.

The experience of the young participant who was not offered the opportunity to freeze her eggs and who believed her race played a role in that decision is striking and concerning. Additionally, her experience of meeting other young Black cancer patients who were also not offered fertility preservation compared to their white counterparts is alarming. Research suggests that fertility preservation is highly underutilized by eligible female cancer patients in Canada (Yee et al., 2012). However, whether there are racial and/or socioeconomic disparities in the utilization of oncofertility services in Canada is unknown. Research from the US indicates that racial, socioeconomic, age, and parity disparities exist in female oncofertility care; women with cancer, those who are Black, of a lower SES, older, and parous have lower rates of fertility preservation (Meernik et al., 2023; Turner et al., 2023). White women are more likely to receive fertility preservation counselling than racialized women, age (older women less likely), marital status, and type of cancer were also associated with counselling (Lawson et al., 2017). A study of young women with cancer in US found disparities in access to fertility preservation disparities based on ethnicity, sexual orientation, age, whether one has a bachelor's degree, or has previous children (Letourneau et al., 2012). For young Black women with early-onset breast cancer in the US, one study found that less than half of the patients were aware of the impact of cancer treatment on their fertility and only 56% reported that their health care providers had discussed fertility with them (Vadaparampil et al., 2012).

The rushed nature of the fertility preservation process and the complex nature of decision making for some patients is an additional consideration for patients who already describe this phase of their journey as overwhelming. The participant who expressed regret over freezing embryos rather than eggs due to her relationship status at the time, suggests the need for more information to be provided to patients regarding their options and/or more time for reproductive counselling.

In Voight et al. (2020)'s New York City-based study, all Black patients accessing fertility preservation services had a partner, indicating that Back women may be more likely to access fertility preservation services when they are in a relationship (Voigt et al., 2020). This finding has significant implications for single Black women of reproductive age. The impact of relationship status on the fertility preservation decisions of Black women is another area that is unexplored.

The participants' experiences with costs associated with fertility preservation, and the limitation of provincial insurance coverage for IVF, suggests that there are financial barriers to fertility preservation for Black patients with breast cancer in Canada. Participants who were able to access fertility preservation explained how they were supported financially by friends, family, or a charity. However, this suggests that women without strong social networks or knowledge of how to access financial support, may be unable to proceed with fertility preservation. In the US, data indicates that race and insurance status may impact a physician's decision to discuss fertility preservation (Mohapatra, 2014). The participant who was not offered fertility preservation explained that her mistreatment may have been due to assumptions made by her physician with respect to her SES. Racial disparities in physician referral to fertility preservation services for breast cancer patients in Canada should be further explored.

5.7 Financial Burden

Participants' experiences highlight the financial impact of breast cancer treatment on their breast cancer journey. Despite universal health care coverage, the low ranking of the Canadian healthcare system for health equity in a Commonwealth Fund report has been attributed to income inequality and structural racism (Nickel et al., 2018). Additionally, Canada is the only

OECD country that provides universal health insurance without universal outpatient prescription drug coverage (Grignon et al., 2020). While there are many studies on healthcare system costs of various breast cancer treatments, out-of-pocket costs and financial burden for patients have been largely unexplored.

One study of out-of-pocket costs for cancer patients in Ontario found that breast cancer patients had significantly higher device costs, family care costs, and total out-of-pocket costs than colorectal, lung, and prostate cancer patients combined (Longo & Bereza, 2011). Out-of-pocket costs that participants mentioned included costs for medication during chemotherapy treatment; lymphedema sleeves; cost of food, including fresh produce; naturopathic services; transportation and parking, especially for daily radiotherapy treatment; and childcare. Out-of-pocket costs are a significant part of the economic burden of cancer (Pisu et al., 2010). In addition to the costs mentioned by participants, food supplements, over-the-counter medications, costs for wigs, and alternative treatment can all be out-of-pocket costs for women undergoing breast cancer treatment (Moore, 1999). Costs at a time when income may also be limited.

Participants' experiences indicate that there are challenges to navigating private and public insurance. Improved communication about insurance coverage is clearly needed. Lack of knowledge on the part of participants and pharmacists about provincial insurance led to miscommunication, a delay in treatment for one participant, and significant financial burden for another.

Some participants mentioned receiving financial support for transportation and/or childcare, while others were not aware that such support was available. The opportunistic nature of services indicates the need for more systematic dissemination of resources available to patients.

Additionally, clearer communication of costs that might be incurred during the breast cancer journey is needed.

Reduction in income due to long-term disability was a key concern for many participants. Wage loss due to work absences for breast cancer treatment has a considerable impact on financial burden for Canadian women with breast cancer (Lauzier et al., 2008, 2013). A study of women with breast cancer in Quebec found that a higher financial burden existed for women with lower education, lower social support, who had invasive disease, received chemotherapy, were self-employed, lived far from the hospital where surgery was performed, had shorter tenure at work, or were employed on a part-time basis (Lauzier et al., 2008).

Participants' reliance on personal savings and financial support from their social circles raises concerns about the financial burden for Black women of lower SES, who have less resources to rely upon. In Ontario, racialized workers are more likely to not have prescription care coverage than white workers (Cheff et al., 2019). Additionally, SES and social class discrimination are significant challenges to receiving health care for racialized people in Toronto (Mahabir et al., 2021). While racial disparities in the financial burden of breast cancer treatment haven't been explored in Canada, in the US, a study conducted in North Carolina found a higher incidence of adverse financial impact of breast cancer treatment for Black women compared to their white counterparts, as well as significant disparities for transportation barriers and job and income loss (Wheeler et al., 2018).

Participants' challenges with medication cost and access are not isolated incidents. A recent scoping review identified structural and institutional barriers in access to medicine for racialized communities in Canada (Moscou, 2023). The financial burden of cancer treatment, including out-of-pocket costs and impacts of wage loss for Black women with cancer requires further exploration. Information about financial support available to eligible patients should be provided in a systematic rather than in a piecemeal fashion, in order to prevent Black women from suffering unduly.

5.8 Lack of Representation

Participants felt unrepresented in breast cancer spaces. They shared experiences of hypervisibility as the sole Black women in clinics or cancer support groups and simultaneously invisible through the lack of representation on breast cancer brochures, in clinical images, or in breast cancer support groups.

Participants also expressed the need for Black representation on their healthcare teams and in breast cancer clinics, as this would help them feel safe, seen and heard. Research indicates that cancer patients from minority groups can benefit from racially concordant care (Crown & Joseph, 2022). A recent study of the obstetric health experiences of Black women in Toronto recommended increased representation of Black health providers and the need for anti-Black racism training (Boakye et al., 2023). This recommendation echoes participants' demands for race concordant care. Additionally, the use of culturally tailored and language concordant nurse and/or patient navigators, improved communication, and education for both patients and providers and are recommended strategies to overcome barriers in breast cancer screening (Patel & Parikh, 2021).

Black physicians and trainees in Ontario report strong bonds with Black patients, however, they also experience racial discrimination from patients, peers and superiors (Mpalirwa, 2020). Black nurses in Canada also experience anti-Black racism and their experiences highlight the need for mandatory anti-Black training to address representation and workplace culture (Prendergast et al., 2023). Black healthcare providers' perspectives echo participants' calls for increased representation in healthcare spaces and education on how to treat Black patients in a way that makes them feel safe.

5.9 Mistrust of the Healthcare System

Participants discussed their trust of the healthcare system as a result of their experiences, which has many implications for current and future health care access and care of Black women with breast cancer. Medical mistrust is a common barrier to breast cancer screening adherence for racialized women (Ponce-Chazarri et al., 2023). Higher levels of medical mistrust are also associated with treatment discordance (failure to start or complete physician-recommended treatment) for women with breast cancer (Dean et al., 2017). Medical mistrust has a negative impact on health for marginalized women (Ho et al., 2022). For African Americans, mistrust of breast cancer treatment and the healthcare system is prevalent (Ferrera et al., 2016). This mistrust has been associated with historical discrimination and medical experimentation of African Americans and the present-day legacies of these events (Ferrera et al., 2016). None of the participants in this study chose not to undergo treatment recommended by their physicians, however, the experiences of Black women who choose not to undergo treatment may simply not have been captured by this study.

Participants mentioned their experiences and frustrations with inadequate communication by their healthcare providers. For young Black women in the US, communication quality of patient-provider interactions was found to significantly predict medical mistrust, with medical mistrust decreasing, as communication quality increased (Adams & Craddock, 2023). Additionally, poor communication between healthcare providers and patients may impact Black women's treatment decision-making and consequently their outcomes (Sheppard et al., 2010). Communication problems for Black women with their providers include feeling unprepared to ask questions and discuss treatment options (Sheppard et al., 2010). Several participants advised Black women to advocate for themselves and ask questions about their treatment. Their experiences highlight the importance of communication training for healthcare providers. Patient-centered communication skills, such as asking patients about their concerns and being responsive to the needs they identify can help mitigate the effects of medical mistrust (Cuevas et al., 2019). The interpersonal aspects of patient-provider interactions can have an impact on perceived quality of care for women with breast cancer (Gonzales et al., 2019).

Participants discussed their experiences with providers dismissing their concerns, which led to a delay in diagnosis for one participant. Participants also mentioned the dismissal of their pain symptoms and inadequate pain management. Dismissal of the pain concerns of Black women in healthcare interactions has been documented in US studies (Adebayo et al., 2022).

Research on racism in healthcare is dominated by US studies, such as Taylor et al. (2007)'s study on the positive association of experiences of racial discrimination with increased incidence of breast cancer for Black women, especially those of a younger age. There is a need for studies that examine other geopolitical contexts (Hamed et al., 2022). For Black Canadians, racial discrimination is prevalent, with Black women experiencing higher levels of everyday and major racial discrimination (Cénat, Hajizadeh, et al., 2021). The establishment of the Black Health Education Collaborative (BHEC) is a response to systemic anti-Black racism, which negatively impacts the health of Black people in Canada (Douglas et al., 2022). Racism and ethnic-based discrimination have been identified as a significant barrier to receiving healthcare by racialized people in Toronto (Mahabir et al., 2021). Experiences of racism, both within and outside of the healthcare system, appear to be widespread for Black Canadians in Toronto and Ottawa (Husbands et al., 2022). The COVID-19 pandemic is a powerful and recent example of the disproportionate health effects on Black people and other racialized communities in Toronto (Mensah & Williams, 2022).

One participant spoke about her mistrust of the healthcare system due to her insider experience, as an occupational therapist. Some Canadian studies have explored the experiences of Black healthcare workers with discrimination. Black nurses in Canada experience subtle but frequent racism in the healthcare setting (Etowa, 2016), as well as culture of silence surrounding racism(Beagan, Bizzeth, & Etowa, 2022). Black women healthcare providers in Canada also experience epistemic racism, where they are deemed less credible, and misogynoir, a specific type of racism towards Black women (Beagan, Bizzeth, Sibbald, et al., 2022). Occurrences of interpersonal, structural, and institutional racism also appear to be common for racialized therapists in the Canadian occupational therapy field (Beagan, Bizzeth, Sibbald, et al., 2022). This evidence of anti-Black racism in Canadian healthcare and the culture of silence is concerning for Black women seeking breast cancer screening and care.

In the US, higher medical mistrust is also related to concern regarding tumor genomic profiling, which is underutilized by African American adults with cancer (Hoadley et al., 2022). Genetic testing and counselling services for hereditary breast and ovarian cancer (BRCA1/2) are underutilized by Black women (Sheppard et al., 2013; Sutton et al., 2019). Black women with higher levels of medical mistrust are less likely to obtain BRCA1/2 genetic testing and counselling (Sheppard et al., 2013; Sutton et al., 2019). It is unknown if racial disparities exist for tumor genomic profiling or genetic testing for breast cancer in Canada, however, underutilization is particularly concerning given the younger ages of participants.

For Black women who have sex with women, stigma and medical mistrust are significantly associated with obtaining routine healthcare (Brenick et al., 2017). Additionally, Black sexual minority women experience multiple marginalized identities and are underrepresented in breast cancer research (Malone et al., 2019). The experiences of Black 2SLGBTQIA+ women with breast cancer care in Canada were not captured by this study due to challenges with recruitment. The impact of medical mistrust on the health behaviours of Black women in Canada, including women whose intersecting identities further marginalize them, need to be explored.

There is increasing recognition of the need to dismantle medical racism to address healthcare disparities. Experts have stressed the need for policy and structural changes as well as community-led solutions to address racism in maternal health (Catalao et al., 2023). The same principles apply and must be undertaken to tackle racism within the breast cancer space. Within the Canadian cancer care sector, while health equity is an increasing priority, there is a lack of clarity and coordination of actions required for meaningful and transformative change (Lambert, 2023). Listening to and understanding Black women's experiences with breast cancer is only the first step. Racial humility, including a commitment to critical evaluation, assessment of accountability, and commitment to transformative action, is required of healthcare leadership in order to dismantle anti-Black racism (Massaquoi 2023).

5.10 Strengths

One of the most important strengths of this research is the community-based approach. The research question was developed out of conversations in the community about what was needed. The trusting relationship between researchers and the community organization facilitated the participation of many who decided to share their stories. Many participants expressed their thanks at the end of the interview for being provided with a safe space to share their experiences and their gratitude that this research was being conducted.

The diversity of participants and the richness of information provided by participants is another strength of this research. Participants were of various ages, migration status, income level, educational backgrounds, religious faiths. The diversity of intersectional identities and engagement of participants allowed for the deep and meaningful exploration of various lived experiences.

5.11 Limitations

There are a number of limitations of this research.

All of the interviews were conducted in English, with participants whose first language was English or who preferred to speak English. Recruitment flyers were printed in English and were shared in English on social media platforms. This limited the participation of the Black francophone community. However, this limitation was addressed through an amendment in the research protocol. This is further discussed in the next section.

All of the interviews were conducted virtually over Zoom. This may have limited the participation of those without easy access to technology, a secure internet connection, or technological literacy. Virtual meetings over Zoom were conducted due to the restrictions posed by the COVID-19 pandemic. However, as restrictions were eased, participants were offered the opportunity to have interviews conducted in-person but all declined the in-person option.

Participants in this study were younger, more educated women. This is not unexpected, given who typically volunteers to participant in research studies. Additionally, the younger demographic, fits with the research that Black women are getting diagnosed younger than their white counterparts. However, there is limited representation of older women (65+) among participants. To address this, the study research protocol was amended to allow for a caregiver to participate in the interview. This was due to feedback from a participant's daughter who explained that her mother's lack or response to questions was due to fatigue, elementary-level education, and forgetfulness. She explained that the mother would benefit from her daughter's participation, as she could prompt her to tell stories that she had shared in the past. This participant did not choose to do a follow-up interview. Other strategies to engage older Black women in the research is needed.

5.12 Conclusion

The purpose of this study was to explore the lived experiences of Black women with breast cancer in Toronto to broaden our understanding in the Canadian context of how race and sociocultural factors shape Black women's journeys. The findings demonstrate that Black women's' experiences are complex and nuanced. Participants' experiences demonstrated the importance of faith and reliance on community support for Black women with breast cancer in Toronto. They emphasized the concerns of young Black women with their fertility options, their hopes for a family after treatment and the complexity of decision making at this time. Participants stressed the financial impact of wage loss and their concerns for the future. They also highlighted the unmet need of Black women with breast cancer with respect to mental health support for themselves and their families. Most importantly, this study brings attention to the experiences of Black women feeling invisible, unseen, and unheard on their breast cancer journeys in Toronto. Understanding these experiences and needs are only the first step to addressing colourblind healthcare policies and dismantling medical racism in Toronto and beyond. Many participants in this study expressed their privilege and conveyed concern for Black women with much less resources than themselves. Healthcare providers, administrators, and policymakers must consider the testimony of lived experience provided by study participants and critical examine how to work towards providing culturally safe and appropriate care for Black women in Canada.

5.13 Recommendations

Findings from this study of the lived experiences of Black women with breast cancer in Toronto provide several important recommendations for policymakers and practitioners as well as future research.

- Participants' experiences of being diagnosed at younger ages and in several cases decades before the age of routine breast screening is alarming. The calls for decreasing the breast cancer screening age for Black women given evidence of earlier incidence should not be ignored.
- Ensuring that all premenopausal Black women with breast cancer have the opportunity to discuss and proceed with fertility preservation if they so desire is another key recommendation. Participants clearly expressed the importance of fertility preservation. The grief of the young Black woman who was not offered fertility preservation on her journey cannot be disregarded.
- Additionally, ensuring that waiting rooms and clinical spaces show more representative imagery can be easily remedied. This can include clinical images of breast cancer on darker skin tones, clinical wig options for Afro-textured hair, prosthetics available in a

range of nude skin tones and referrals to resources, such as the Olive Branch of Hope, that cater to Black and racialized women.

There are a number of recommendations for further research. Several demographic groups were not able to be recruited successfully. Women with a low-income level, not due to disability leave status, and lower education levels are not adequately represented in the study. Several participants when discussing their challenges often mentioned their privilege and not knowing how women without resources would cope. The experiences of Black women with low incomes and/or on social assistance needs further study.

While there was significant representation of foreign-born women in the study, including newcomers, none of the participants were refugees. Black refugees experiencing breast cancer will likely have different experiences compared to Canadian-born women, established immigrants, or newcomers coming through economic or family streams. Recruitment of refugees, especially non-English speakers, is a research gap.

None of the participants identified as 2SLGBTQIA+ or any gender other than female, so our sample lacked sexual and gender diversity. None of the research team members identified as 2SLGBTQIA+ which likely contributed to limited access to members of this community. Having Black queer representation on the research team would add value to the study to address this gap.

The majority of participants who discussed their faith or religion identified as Christian. Only one of the participants identified as Muslim. From an intersectional lens, Black Muslims in Canada face Islamophobia both within Black communities and in Canadian society at large. More targeted outreach to Muslim communities is needed to explore how their experiences may differ. The data may be enriched through outreach to religious minorities in the Black community, such as Rastafarians, who are also not represented in the data.

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Appendices

Appendix A: Research Recruitment Flyer

Approved for Posting
Until 31-Aug-2022
Mount Sinai Hospital
Research Ethics Board

RESEARCH STUDY: UNDERSTANDING AND ENHANCING THE CARE EXPERIENCES OF BLACK WOMEN ALONG THE BREAST CANCER JOURNEY

Black Women's Experiences with Breast Cancer Care

We're looking for adults (18+) who self-identify as Women of Black, Caribbean, or African ancestry and are or previously have been diagnosed with breast cancer.

Participants will be asked to participate in:

- 1 - 2 online one-on-one interviews with a researcher, lasting about 1 hour.
- A short demographic survey

(Participants will receive monetary compensation for your time)

Our team:
Dr. Aisha Lofters, Dr. Juliet Daniel, Leila Springer, Dr. Frances Wright, Dr. Gayathri Naganathan, Ielaf Khalil

Research Study Principle Investigator:
Dr. Andrea Covelli, MD PhD
Surgical Oncologist — Breast & Melanoma
Mount Sinai Health System & Princess Margaret Cancer Centre
University of Toronto Department of Surgery,
Division of General Surgery
Andrea.Covelli@uhn.ca
416-586-4800 ext 5227

Please contact:
Miah Zammit - miah.zammit@uhn.ca
Project Coordinator,
Cancer Experience Program and GIPPEC
437-855-6513

Scan here:

Partners

Sinai Health | Mount Sinai Hospital
Joseph & Wolf Lebovic Health Complex

The Olive Branch of Hope
Cancer Support Services

UHN
Toronto General
Toronto Western
Princess Margaret
Toronto Rehab
Michener Institute

WCH WOMEN'S COLLEGE HOSPITAL
Healthcare | REVOLUTIONIZED

Canadian Cancer Society
Société canadienne du cancer

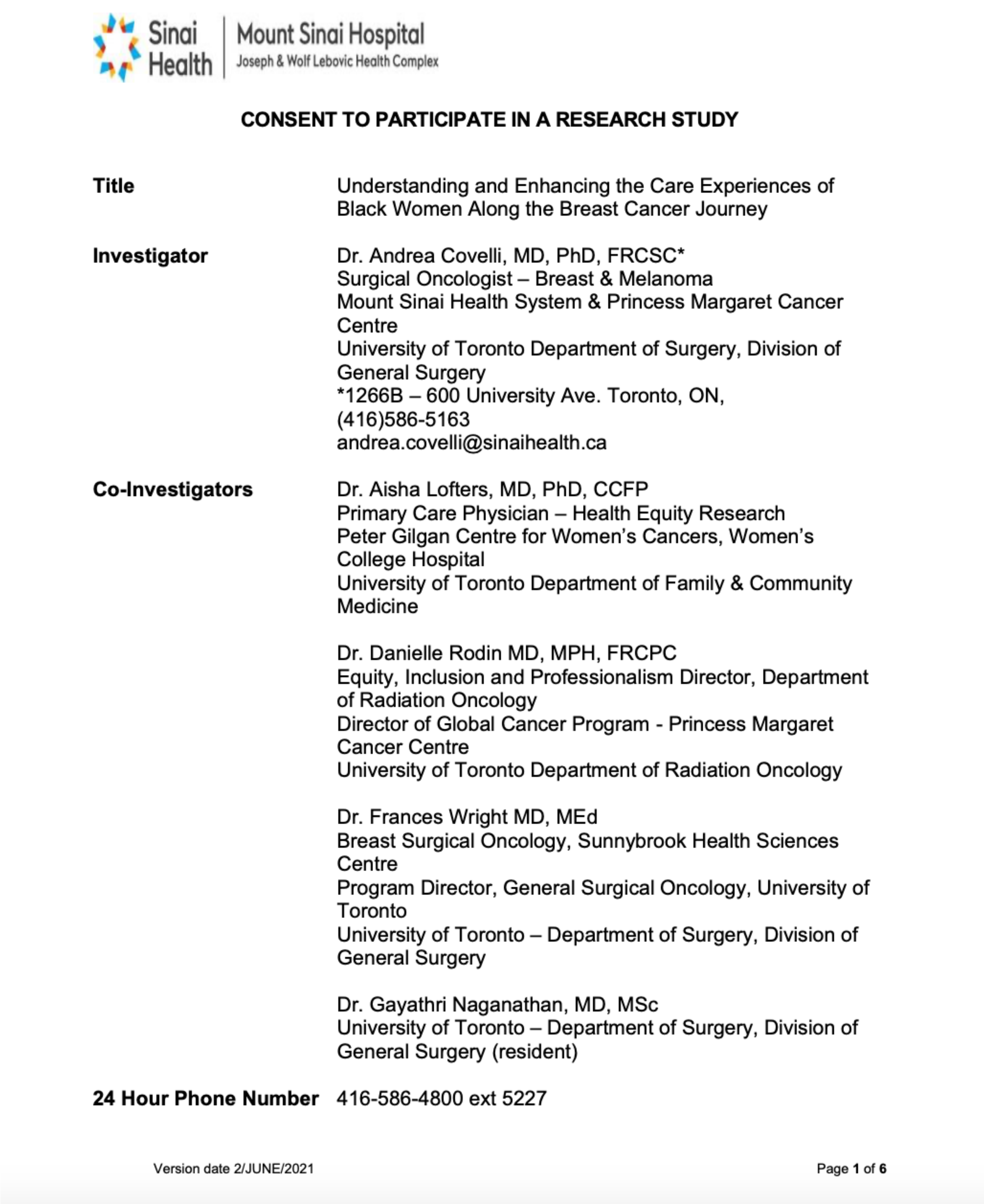
CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

CanImpact®
Improving Cancer Care Together

Email Disclaimer: Please note if you choose to send an email, email messages are not encrypted on the hospital email system and, therefore, the hospital cannot guarantee the security of the messages that you send or receive. Messages may be forged, forwarded, kept indefinitely, or seen by others using the internet. Do not use email to discuss information you think is sensitive or confidential. Do not use email in an emergency since email may be delayed. By sending an email, you acknowledge that you accept this.

Version 8 May 10, 2022

Appendix B: Participant Consent Form



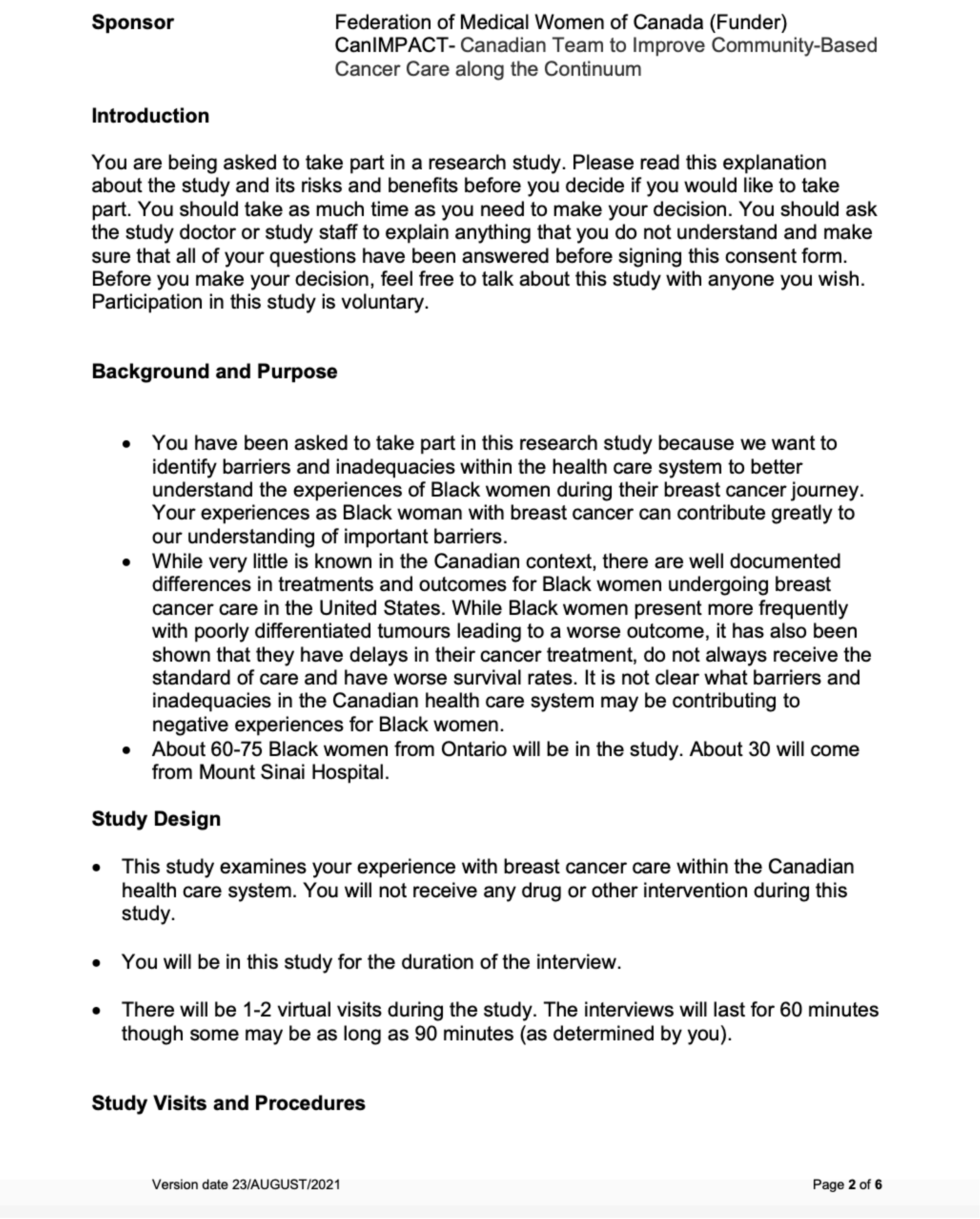
Sinai Health | Mount Sinai Hospital
Joseph & Wolf Lebovic Health Complex

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title	Understanding and Enhancing the Care Experiences of Black Women Along the Breast Cancer Journey
Investigator	Dr. Andrea Covelli, MD, PhD, FRCSC* Surgical Oncologist – Breast & Melanoma Mount Sinai Health System & Princess Margaret Cancer Centre University of Toronto Department of Surgery, Division of General Surgery *1266B – 600 University Ave. Toronto, ON, (416)586-5163 andrea.covelli@sinaihealth.ca
Co-Investigators	Dr. Aisha Lofters, MD, PhD, CCFP Primary Care Physician – Health Equity Research Peter Gilgan Centre for Women's Cancers, Women's College Hospital University of Toronto Department of Family & Community Medicine
	Dr. Danielle Rodin MD, MPH, FRCPC Equity, Inclusion and Professionalism Director, Department of Radiation Oncology Director of Global Cancer Program - Princess Margaret Cancer Centre University of Toronto Department of Radiation Oncology
	Dr. Frances Wright MD, MEd Breast Surgical Oncology, Sunnybrook Health Sciences Centre Program Director, General Surgical Oncology, University of Toronto University of Toronto – Department of Surgery, Division of General Surgery
	Dr. Gayathri Naganathan, MD, MSc University of Toronto – Department of Surgery, Division of General Surgery (resident)
24 Hour Phone Number	416-586-4800 ext 5227

Version date 2/JUNE/2021

Page **1** of **6**



Sponsor Federation of Medical Women of Canada (Funder)
CanIMPACT- Canadian Team to Improve Community-Based Cancer Care along the Continuum

Introduction

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

Background and Purpose

- You have been asked to take part in this research study because we want to identify barriers and inadequacies within the health care system to better understand the experiences of Black women during their breast cancer journey. Your experiences as Black woman with breast cancer can contribute greatly to our understanding of important barriers.
- While very little is known in the Canadian context, there are well documented differences in treatments and outcomes for Black women undergoing breast cancer care in the United States. While Black women present more frequently with poorly differentiated tumours leading to a worse outcome, it has also been shown that they have delays in their cancer treatment, do not always receive the standard of care and have worse survival rates. It is not clear what barriers and inadequacies in the Canadian health care system may be contributing to negative experiences for Black women.
- About 60-75 Black women from Ontario will be in the study. About 30 will come from Mount Sinai Hospital.

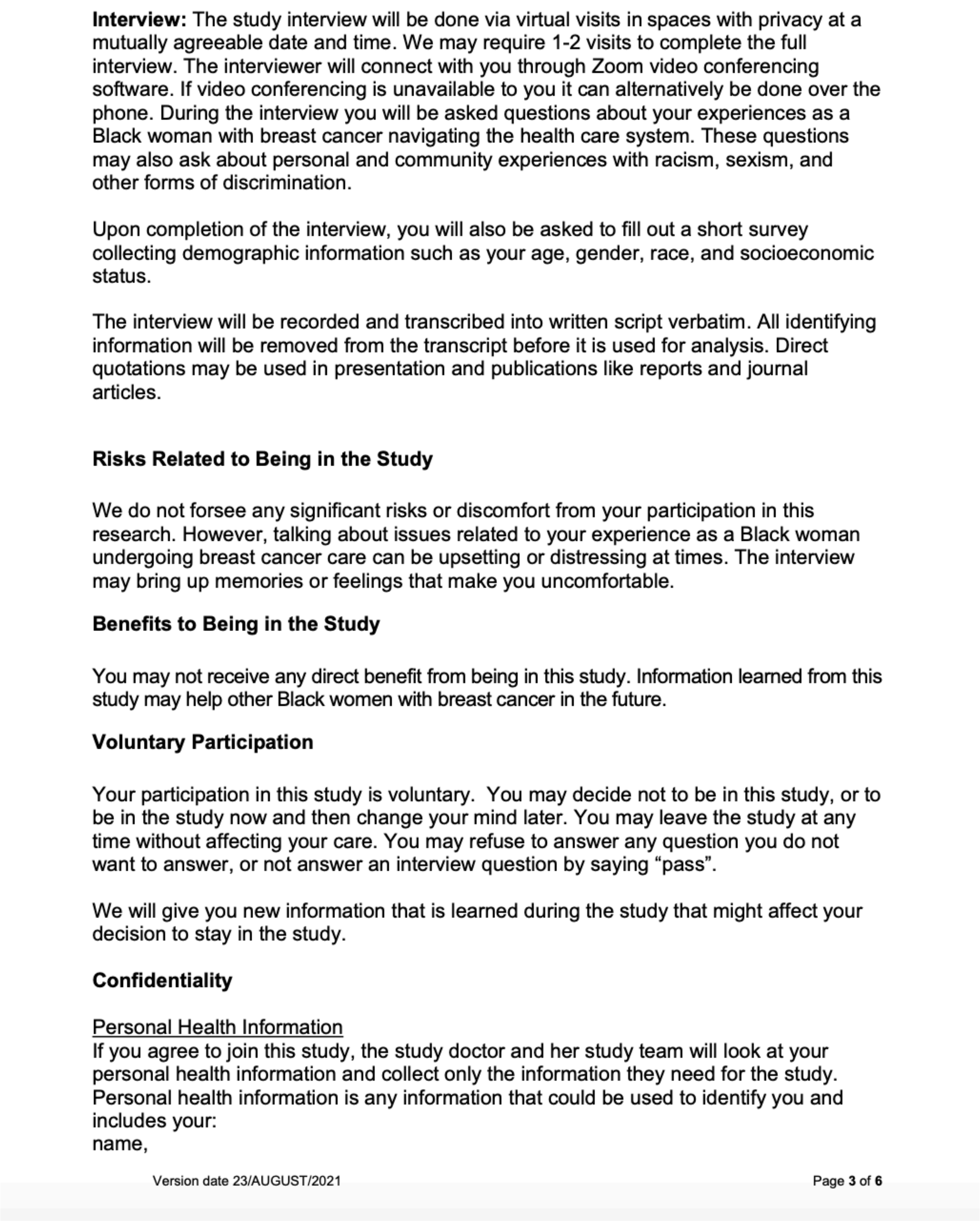
Study Design

- This study examines your experience with breast cancer care within the Canadian health care system. You will not receive any drug or other intervention during this study.

- You will be in this study for the duration of the interview.

- There will be 1-2 virtual visits during the study. The interviews will last for 60 minutes though some may be as long as 90 minutes (as determined by you).

Study Visits and Procedures



Interview: The study interview will be done via virtual visits in spaces with privacy at a mutually agreeable date and time. We may require 1-2 visits to complete the full interview. The interviewer will connect with you through Zoom video conferencing software. If video conferencing is unavailable to you it can alternatively be done over the phone. During the interview you will be asked questions about your experiences as a Black woman with breast cancer navigating the health care system. These questions may also ask about personal and community experiences with racism, sexism, and other forms of discrimination.

Upon completion of the interview, you will also be asked to fill out a short survey collecting demographic information such as your age, gender, race, and socioeconomic status.

The interview will be recorded and transcribed into written script verbatim. All identifying information will be removed from the transcript before it is used for analysis. Direct quotations may be used in presentation and publications like reports and journal articles.

Risks Related to Being in the Study

We do not forsee any significant risks or discomfort from your participation in this research. However, talking about issues related to your experience as a Black woman undergoing breast cancer care can be upsetting or distressing at times. The interview may bring up memories or feelings that make you uncomfortable.

Benefits to Being in the Study

You may not receive any direct benefit from being in this study. Information learned from this study may help other Black women with breast cancer in the future.

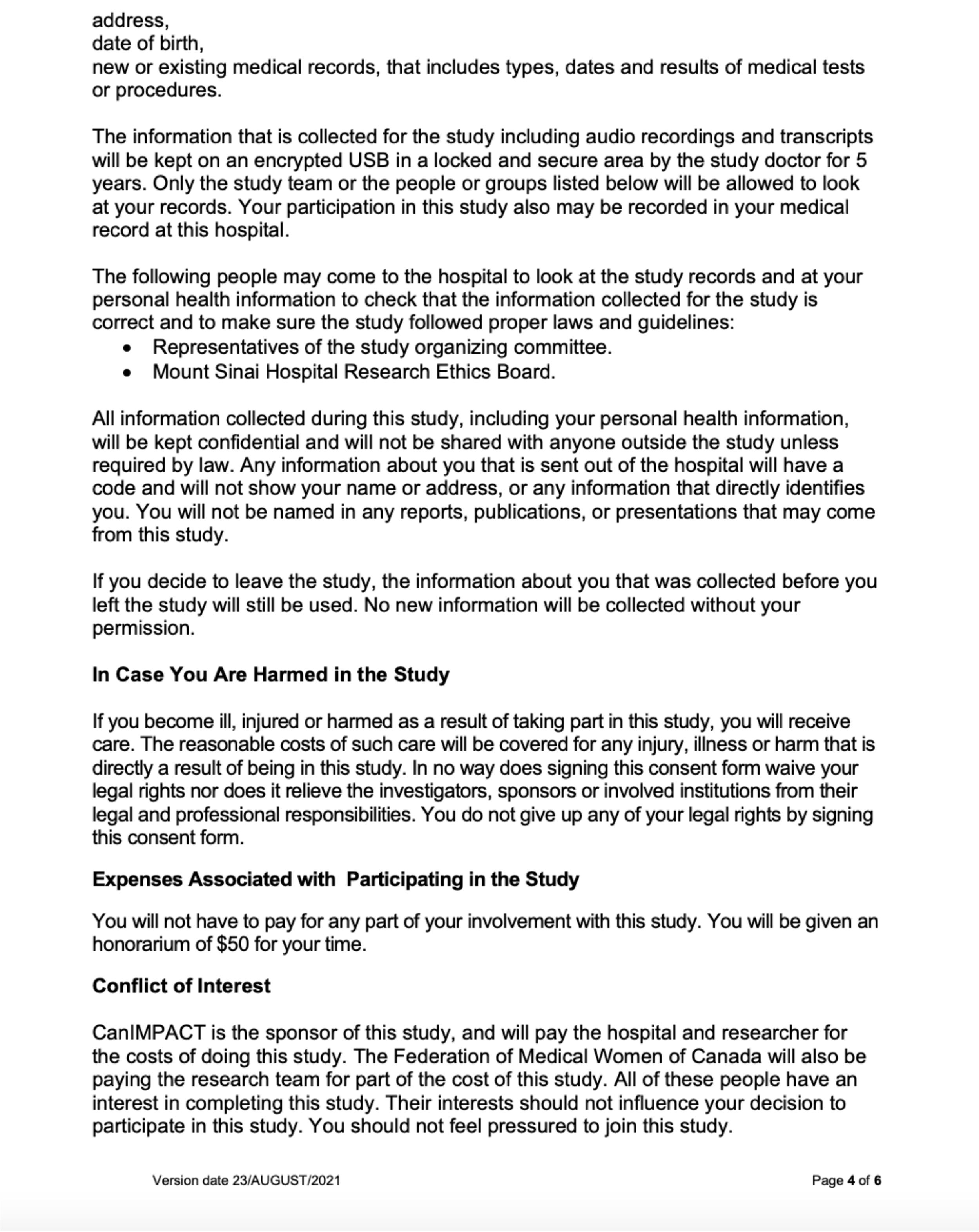
Voluntary Participation

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your care. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

We will give you new information that is learned during the study that might affect your decision to stay in the study.

Confidentiality

Personal Health Information
If you agree to join this study, the study doctor and her study team will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could be used to identify you and includes your:
name,



address,
date of birth,
new or existing medical records, that includes types, dates and results of medical tests or procedures.

The information that is collected for the study including audio recordings and transcripts will be kept on an encrypted USB in a locked and secure area by the study doctor for 5 years. Only the study team or the people or groups listed below will be allowed to look at your records. Your participation in this study also may be recorded in your medical record at this hospital.

The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines:

- Representatives of the study organizing committee.
- Mount Sinai Hospital Research Ethics Board.

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. Any information about you that is sent out of the hospital will have a code and will not show your name or address, or any information that directly identifies you. You will not be named in any reports, publications, or presentations that may come from this study.

If you decide to leave the study, the information about you that was collected before you left the study will still be used. No new information will be collected without your permission.

In Case You Are Harmed in the Study

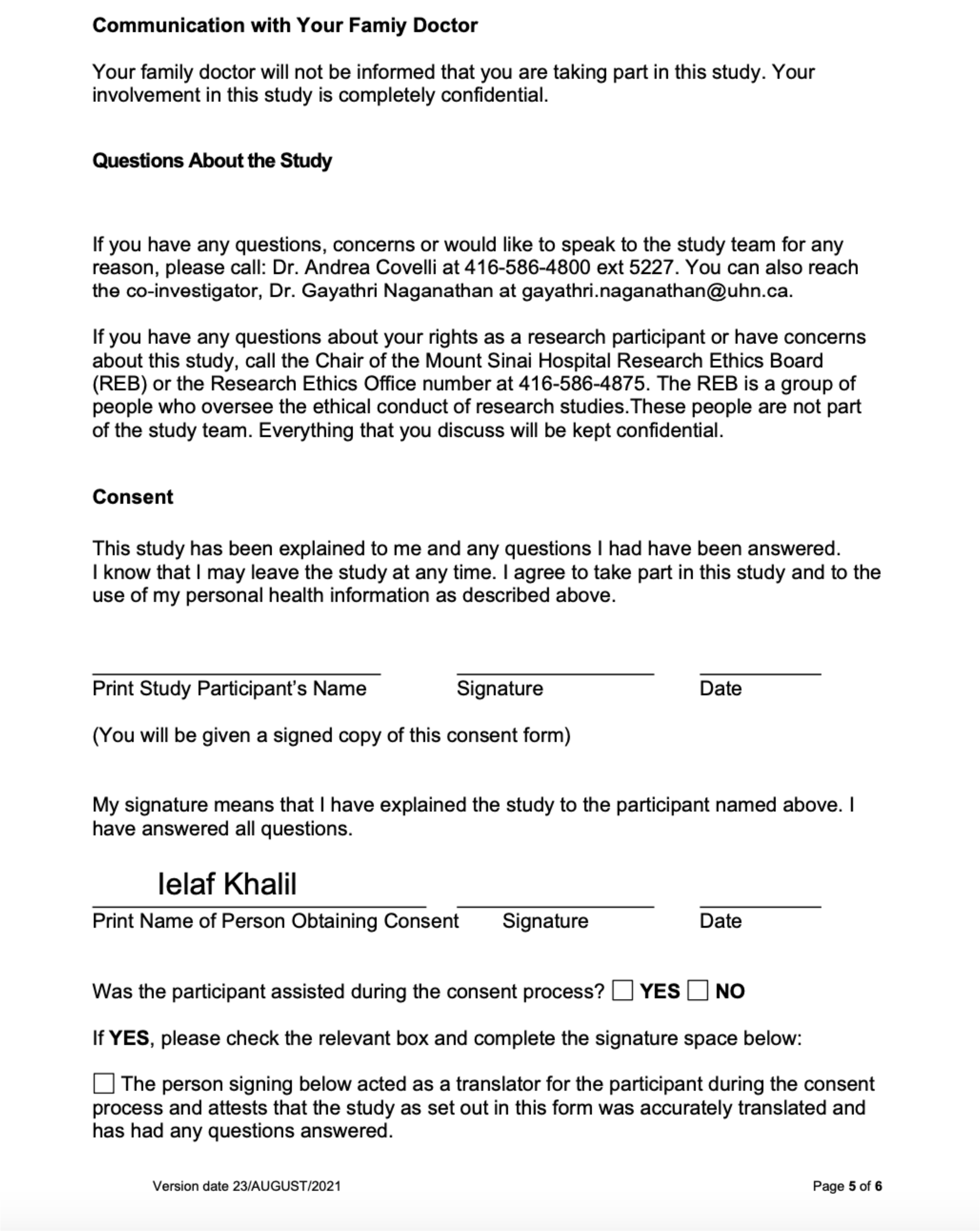
If you become ill, injured or harmed as a result of taking part in this study, you will receive care. The reasonable costs of such care will be covered for any injury, illness or harm that is directly a result of being in this study. In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities. You do not give up any of your legal rights by signing this consent form.

Expenses Associated with Participating in the Study

You will not have to pay for any part of your involvement with this study. You will be given an honorarium of $50 for your time.

Conflict of Interest

CanIMPACT is the sponsor of this study, and will pay the hospital and researcher for the costs of doing this study. The Federation of Medical Women of Canada will also be paying the research team for part of the cost of this study. All of these people have an interest in completing this study. Their interests should not influence your decision to participate in this study. You should not feel pressured to join this study.



Communication with Your Famiy Doctor

Your family doctor will not be informed that you are taking part in this study. Your involvement in this study is completely confidential.

Questions About the Study

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Dr. Andrea Covelli at 416-586-4800 ext 5227. You can also reach the co-investigator, Dr. Gayathri Naganathan at gayathri.naganathan@uhn.ca.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the Mount Sinai Hospital Research Ethics Board (REB) or the Research Ethics Office number at 416-586-4875. The REB is a group of people who oversee the ethical conduct of research studies.These people are not part of the study team. Everything that you discuss will be kept confidential.

Consent

This study has been explained to me and any questions I had have been answered.
I know that I may leave the study at any time. I agree to take part in this study and to the use of my personal health information as described above.

Print Study Participant's Name	Signature	Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

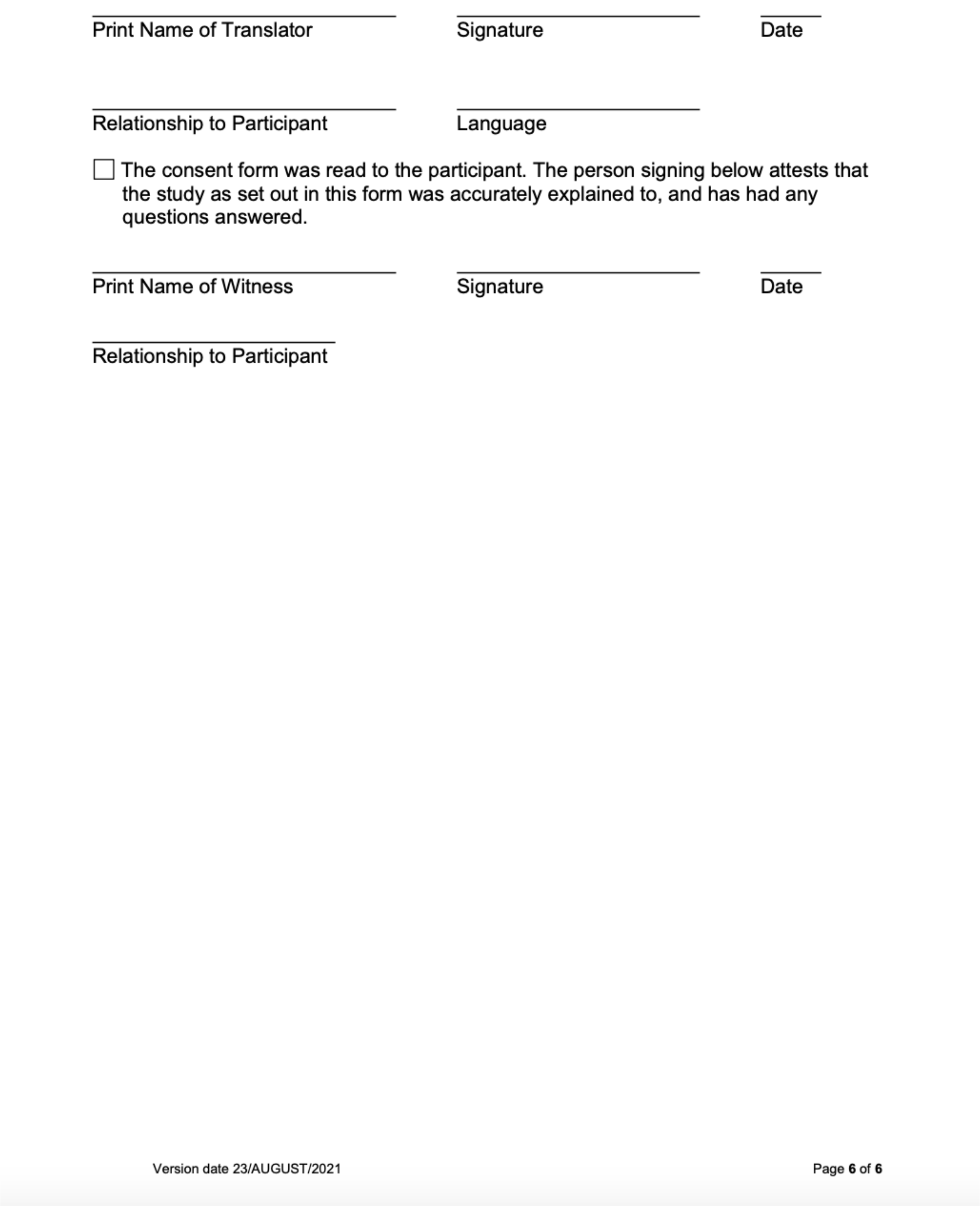
Ielaf Khalil		
Print Name of Person Obtaining Consent	Signature	Date

Was the participant assisted during the consent process? ☐ **YES** ☐ **NO**

If **YES**, please check the relevant box and complete the signature space below:

☐ The person signing below acted as a translator for the participant during the consent process and attests that the study as set out in this form was accurately translated and has had any questions answered.

Version date 23/AUGUST/2021 Page **5** of **6**



Print Name of Translator ____________ Signature ____________ Date ______

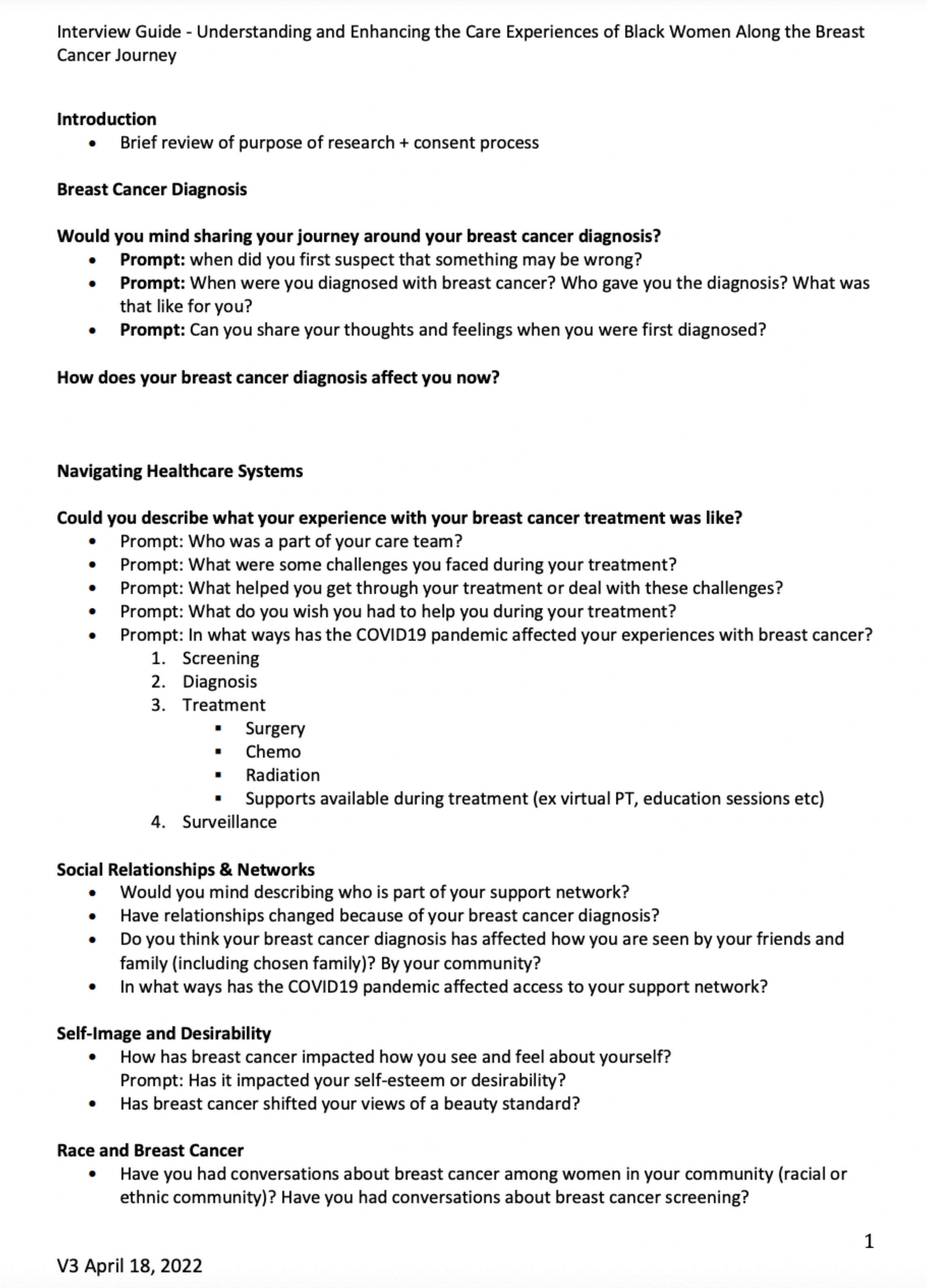
Relationship to Participant ____________ Language ____________

☐ The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

Print Name of Witness ____________ Signature ____________ Date ______

Relationship to Participant ____________

Appendix C: Participant Interview Guide



Interview Guide - Understanding and Enhancing the Care Experiences of Black Women Along the Breast Cancer Journey

Introduction

- Brief review of purpose of research + consent process

Breast Cancer Diagnosis

Would you mind sharing your journey around your breast cancer diagnosis?

- **Prompt:** when did you first suspect that something may be wrong?
- **Prompt:** When were you diagnosed with breast cancer? Who gave you the diagnosis? What was that like for you?
- **Prompt:** Can you share your thoughts and feelings when you were first diagnosed?

How does your breast cancer diagnosis affect you now?

Navigating Healthcare Systems

Could you describe what your experience with your breast cancer treatment was like?

- Prompt: Who was a part of your care team?
- Prompt: What were some challenges you faced during your treatment?
- Prompt: What helped you get through your treatment or deal with these challenges?
- Prompt: What do you wish you had to help you during your treatment?
- Prompt: In what ways has the COVID19 pandemic affected your experiences with breast cancer?
    1. Screening
    2. Diagnosis
    3. Treatment
        - Surgery
        - Chemo
        - Radiation
        - Supports available during treatment (ex virtual PT, education sessions etc)
    4. Surveillance

Social Relationships & Networks

- Would you mind describing who is part of your support network?
- Have relationships changed because of your breast cancer diagnosis?
- Do you think your breast cancer diagnosis has affected how you are seen by your friends and family (including chosen family)? By your community?
- In what ways has the COVID19 pandemic affected access to your support network?

Self-Image and Desirability

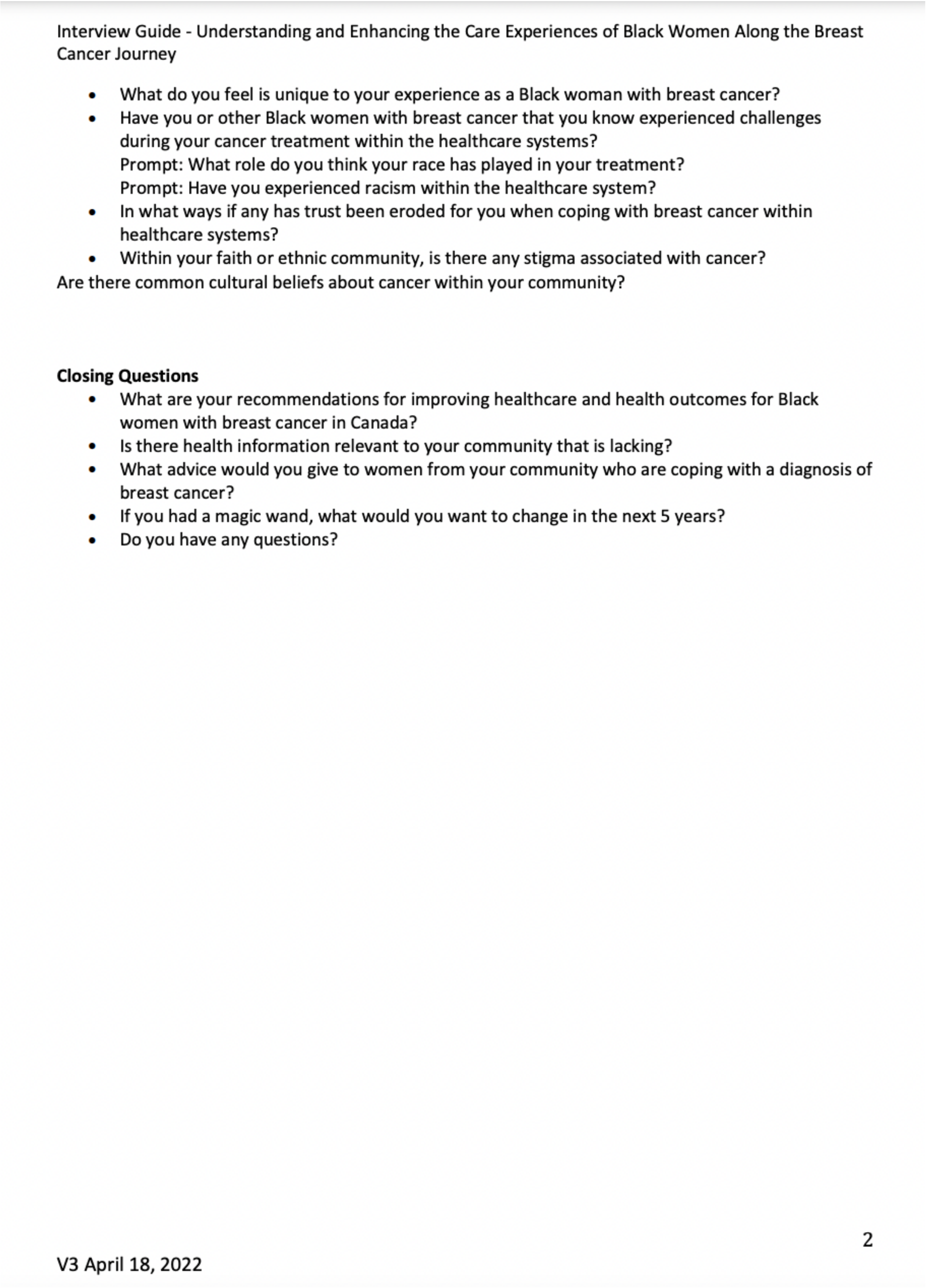
- How has breast cancer impacted how you see and feel about yourself?
  Prompt: Has it impacted your self-esteem or desirability?
- Has breast cancer shifted your views of a beauty standard?

Race and Breast Cancer

- Have you had conversations about breast cancer among women in your community (racial or ethnic community)? Have you had conversations about breast cancer screening?

1

V3 April 18, 2022



Interview Guide - Understanding and Enhancing the Care Experiences of Black Women Along the Breast Cancer Journey

- What do you feel is unique to your experience as a Black woman with breast cancer?
- Have you or other Black women with breast cancer that you know experienced challenges during your cancer treatment within the healthcare systems?
  Prompt: What role do you think your race has played in your treatment?
  Prompt: Have you experienced racism within the healthcare system?
- In what ways if any has trust been eroded for you when coping with breast cancer within healthcare systems?
- Within your faith or ethnic community, is there any stigma associated with cancer?

Are there common cultural beliefs about cancer within your community?

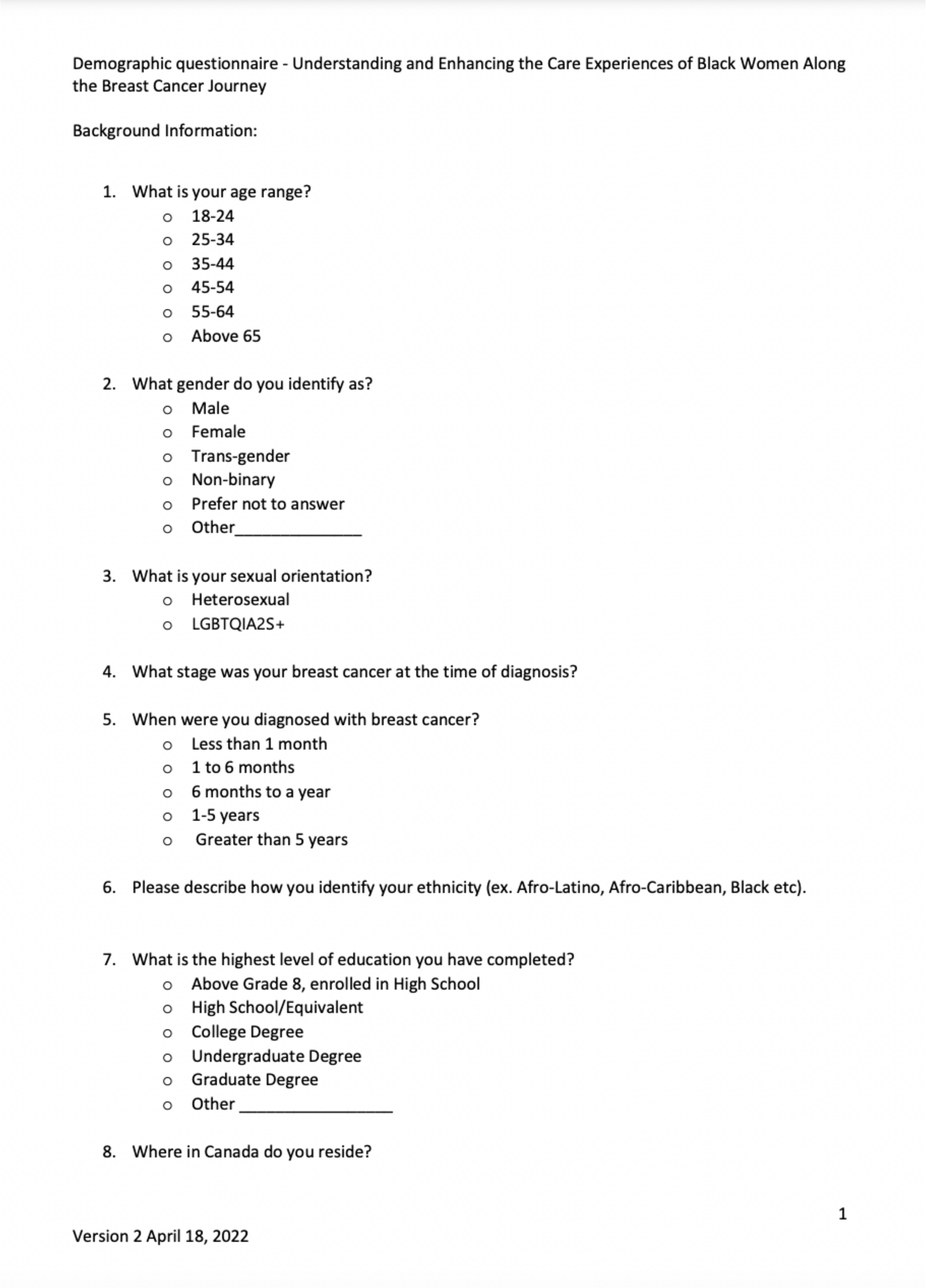
Closing Questions

- What are your recommendations for improving healthcare and health outcomes for Black women with breast cancer in Canada?
- Is there health information relevant to your community that is lacking?
- What advice would you give to women from your community who are coping with a diagnosis of breast cancer?
- If you had a magic wand, what would you want to change in the next 5 years?
- Do you have any questions?

2

V3 April 18, 2022

Appendix D: Participant Demographic Questionnaire



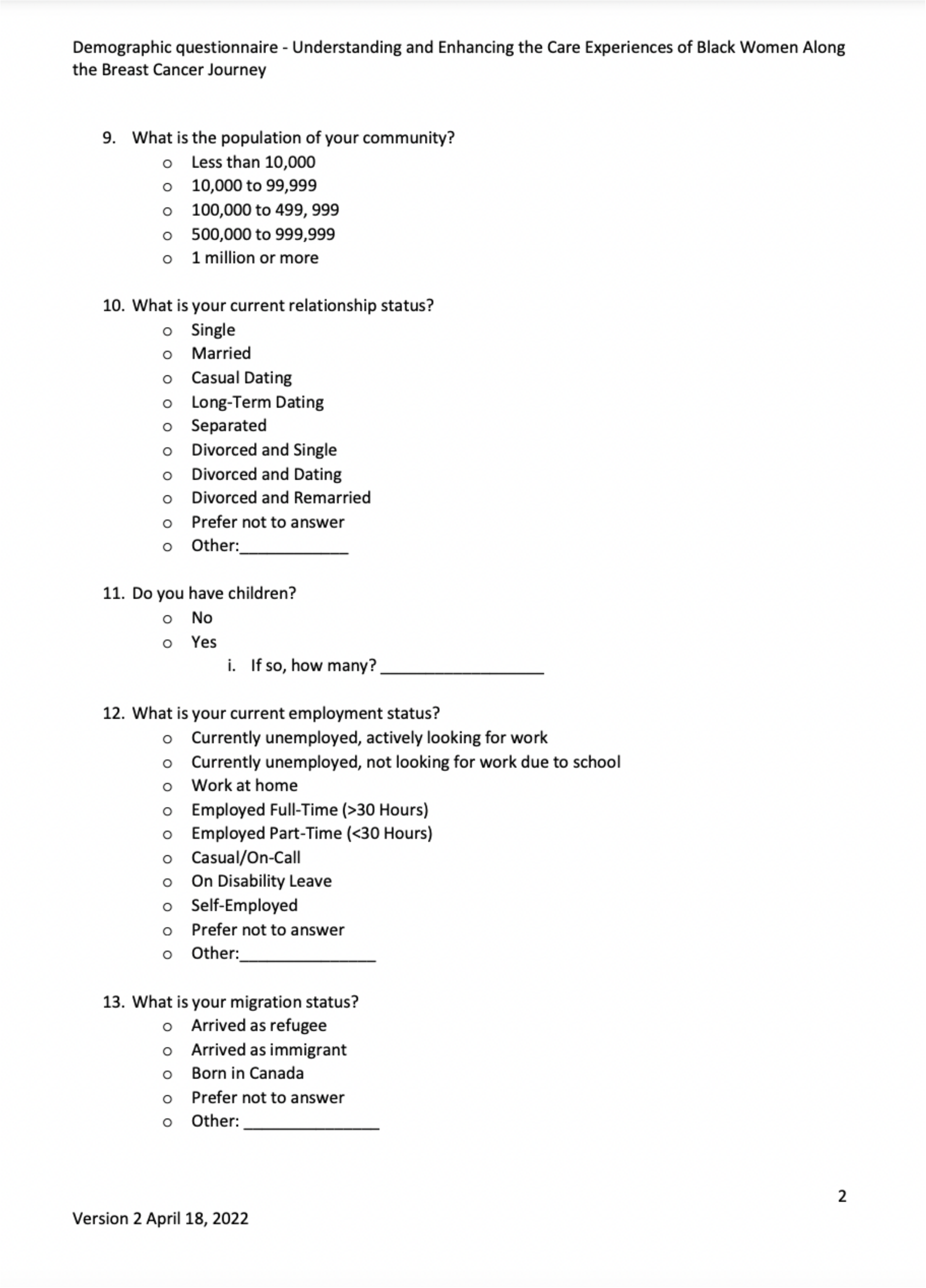
Demographic questionnaire - Understanding and Enhancing the Care Experiences of Black Women Along the Breast Cancer Journey

Background Information:

1. What is your age range?
   - 18-24
   - 25-34
   - 35-44
   - 45-54
   - 55-64
   - Above 65
2. What gender do you identify as?
   - Male
   - Female
   - Trans-gender
   - Non-binary
   - Prefer not to answer
   - Other______________
3. What is your sexual orientation?
   - Heterosexual
   - LGBTQIA2S+
4. What stage was your breast cancer at the time of diagnosis?
5. When were you diagnosed with breast cancer?
   - Less than 1 month
   - 1 to 6 months
   - 6 months to a year
   - 1-5 years
   - Greater than 5 years
6. Please describe how you identify your ethnicity (ex. Afro-Latino, Afro-Caribbean, Black etc).
7. What is the highest level of education you have completed?
   - Above Grade 8, enrolled in High School
   - High School/Equivalent
   - College Degree
   - Undergraduate Degree
   - Graduate Degree
   - Other ________________
8. Where in Canada do you reside?

1

Version 2 April 18, 2022



Demographic questionnaire - Understanding and Enhancing the Care Experiences of Black Women Along the Breast Cancer Journey

9. What is the population of your community?
    - Less than 10,000
    - 10,000 to 99,999
    - 100,000 to 499, 999
    - 500,000 to 999,999
    - 1 million or more

10. What is your current relationship status?
    - Single
    - Married
    - Casual Dating
    - Long-Term Dating
    - Separated
    - Divorced and Single
    - Divorced and Dating
    - Divorced and Remarried
    - Prefer not to answer
    - Other:____________

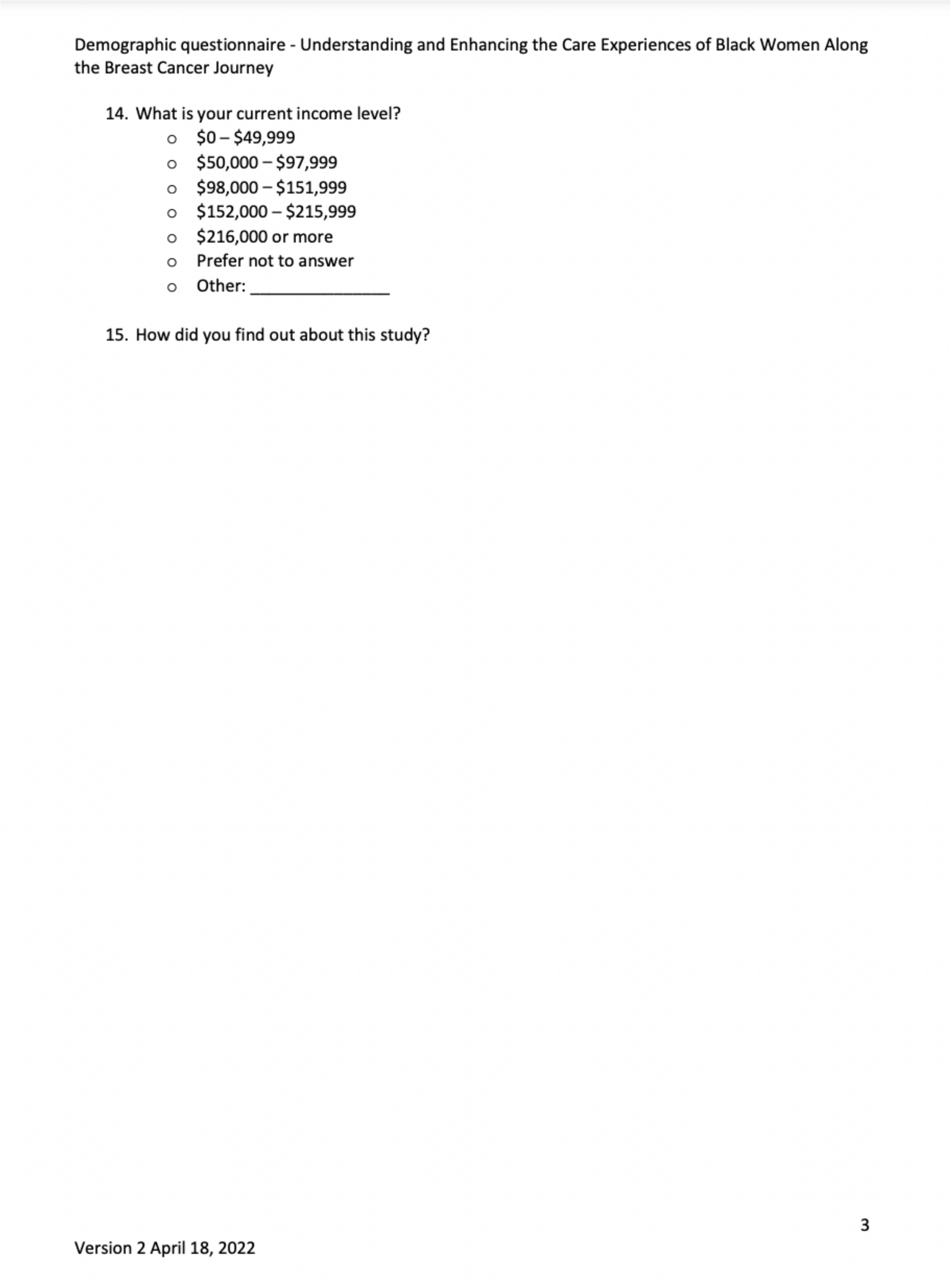
11. Do you have children?
    - No
    - Yes
        i. If so, how many? __________________

12. What is your current employment status?
    - Currently unemployed, actively looking for work
    - Currently unemployed, not looking for work due to school
    - Work at home
    - Employed Full-Time (>30 Hours)
    - Employed Part-Time (<30 Hours)
    - Casual/On-Call
    - On Disability Leave
    - Self-Employed
    - Prefer not to answer
    - Other:_______________

13. What is your migration status?
    - Arrived as refugee
    - Arrived as immigrant
    - Born in Canada
    - Prefer not to answer
    - Other: _______________

2

Version 2 April 18, 2022



Demographic questionnaire - Understanding and Enhancing the Care Experiences of Black Women Along the Breast Cancer Journey

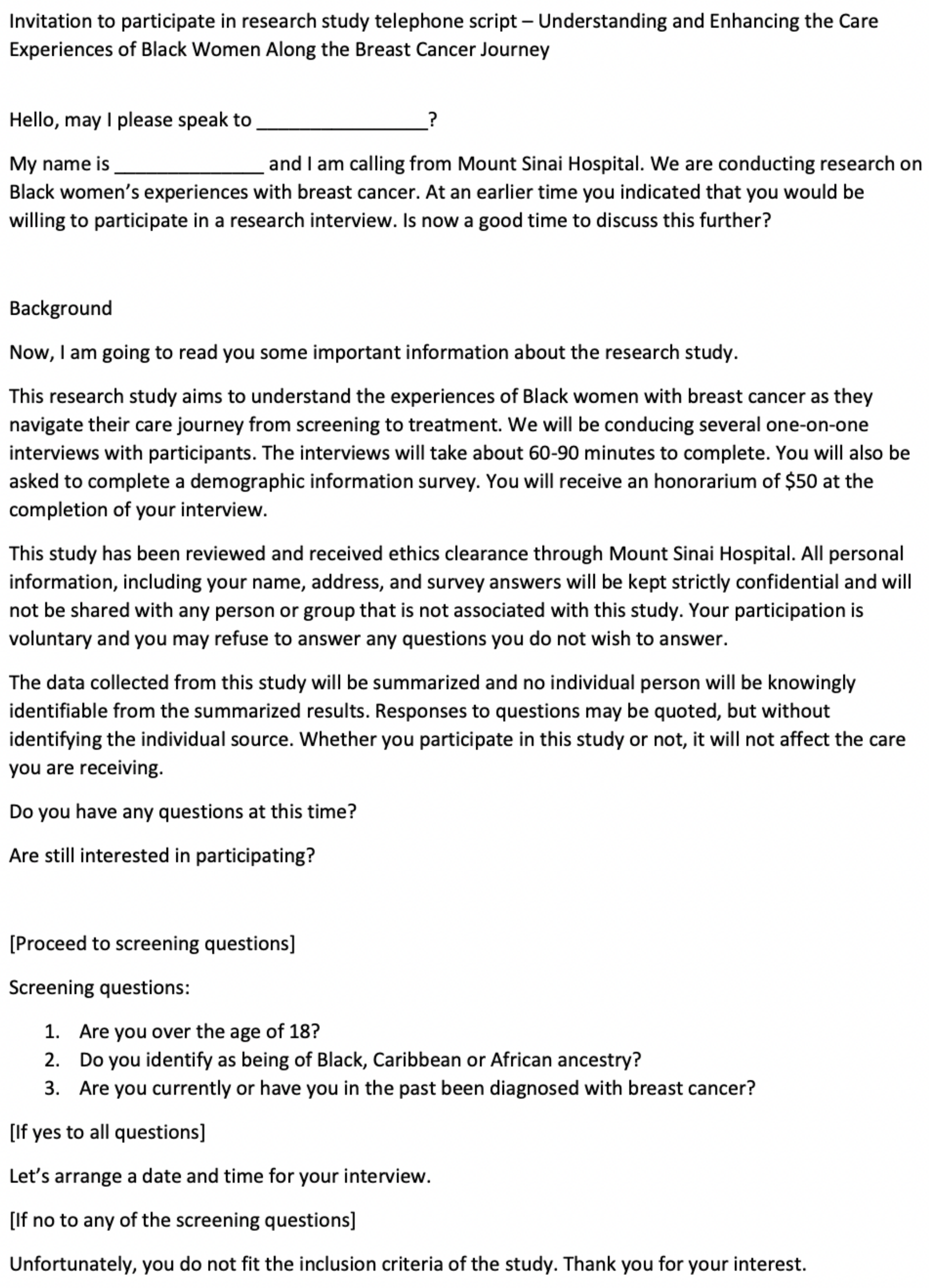
14. What is your current income level?
    - $0 – $49,999
    - $50,000 – $97,999
    - $98,000 – $151,999
    - $152,000 – $215,999
    - $216,000 or more
    - Prefer not to answer
    - Other: _______________

15. How did you find out about this study?

3

Version 2 April 18, 2022

Appendix E: Telephone Script



Invitation to participate in research study telephone script – Understanding and Enhancing the Care Experiences of Black Women Along the Breast Cancer Journey

Hello, may I please speak to ________________?

My name is ______________ and I am calling from Mount Sinai Hospital. We are conducting research on Black women's experiences with breast cancer. At an earlier time you indicated that you would be willing to participate in a research interview. Is now a good time to discuss this further?

Background

Now, I am going to read you some important information about the research study.

This research study aims to understand the experiences of Black women with breast cancer as they navigate their care journey from screening to treatment. We will be conducing several one-on-one interviews with participants. The interviews will take about 60-90 minutes to complete. You will also be asked to complete a demographic information survey. You will receive an honorarium of $50 at the completion of your interview.

This study has been reviewed and received ethics clearance through Mount Sinai Hospital. All personal information, including your name, address, and survey answers will be kept strictly confidential and will not be shared with any person or group that is not associated with this study. Your participation is voluntary and you may refuse to answer any questions you do not wish to answer.

The data collected from this study will be summarized and no individual person will be knowingly identifiable from the summarized results. Responses to questions may be quoted, but without identifying the individual source. Whether you participate in this study or not, it will not affect the care you are receiving.

Do you have any questions at this time?

Are still interested in participating?

[Proceed to screening questions]

Screening questions:

1. Are you over the age of 18?
2. Do you identify as being of Black, Caribbean or African ancestry?
3. Are you currently or have you in the past been diagnosed with breast cancer?

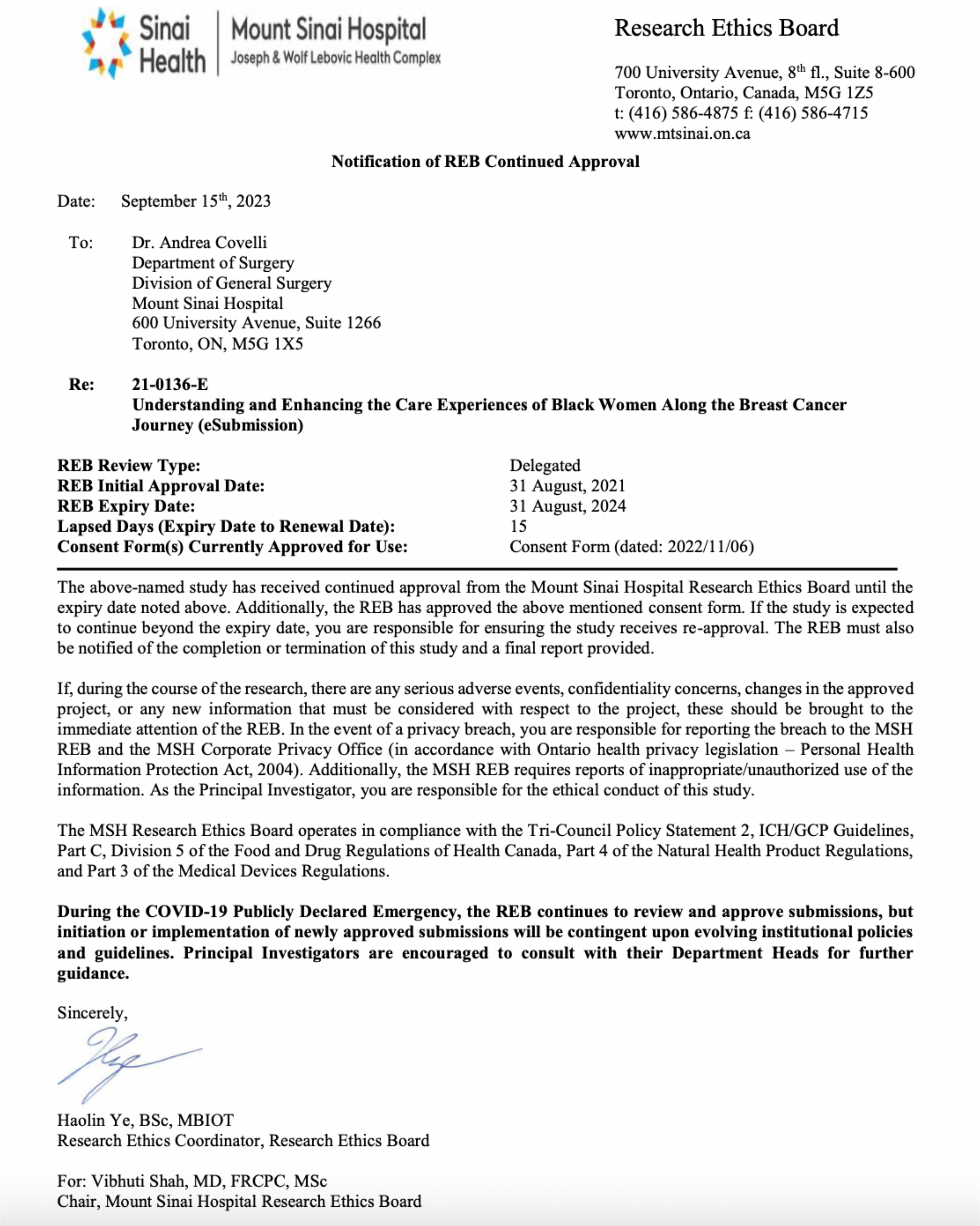
[If yes to all questions]

Let's arrange a date and time for your interview.

[If no to any of the screening questions]

Unfortunately, you do not fit the inclusion criteria of the study. Thank you for your interest.

Appendix F: REB Approval Letter



Sinai Health | Mount Sinai Hospital
Joseph & Wolf Lebovic Health Complex

Research Ethics Board

700 University Avenue, 8th fl., Suite 8-600
Toronto, Ontario, Canada, M5G 1Z5
t: (416) 586-4875 f: (416) 586-4715
www.mtsinai.on.ca

Notification of REB Continued Approval

Date: September 15th, 2023

To: Dr. Andrea Covelli
Department of Surgery
Division of General Surgery
Mount Sinai Hospital
600 University Avenue, Suite 1266
Toronto, ON, M5G 1X5

Re: 21-0136-E
Understanding and Enhancing the Care Experiences of Black Women Along the Breast Cancer Journey (eSubmission)

REB Review Type:	Delegated
REB Initial Approval Date:	31 August, 2021
REB Expiry Date:	31 August, 2024
Lapsed Days (Expiry Date to Renewal Date):	15
Consent Form(s) Currently Approved for Use:	Consent Form (dated: 2022/11/06)

The above-named study has received continued approval from the Mount Sinai Hospital Research Ethics Board until the expiry date noted above. Additionally, the REB has approved the above mentioned consent form. If the study is expected to continue beyond the expiry date, you are responsible for ensuring the study receives re-approval. The REB must also be notified of the completion or termination of this study and a final report provided.

If, during the course of the research, there are any serious adverse events, confidentiality concerns, changes in the approved project, or any new information that must be considered with respect to the project, these should be brought to the immediate attention of the REB. In the event of a privacy breach, you are responsible for reporting the breach to the MSH REB and the MSH Corporate Privacy Office (in accordance with Ontario health privacy legislation – Personal Health Information Protection Act, 2004). Additionally, the MSH REB requires reports of inappropriate/unauthorized use of the information. As the Principal Investigator, you are responsible for the ethical conduct of this study.

The MSH Research Ethics Board operates in compliance with the Tri-Council Policy Statement 2, ICH/GCP Guidelines, Part C, Division 5 of the Food and Drug Regulations of Health Canada, Part 4 of the Natural Health Product Regulations, and Part 3 of the Medical Devices Regulations.

During the COVID-19 Publicly Declared Emergency, the REB continues to review and approve submissions, but initiation or implementation of newly approved submissions will be contingent upon evolving institutional policies and guidelines. Principal Investigators are encouraged to consult with their Department Heads for further guidance.

Sincerely,

Haolin Ye, BSc, MBIOT
Research Ethics Coordinator, Research Ethics Board

For: Vibhuti Shah, MD, FRCPC, MSc
Chair, Mount Sinai Hospital Research Ethics Board

Appendix G: Thematic Map