Jane Bancroft Robinson Foundation Comprehensive Cancer Patient Navigation Landscape Analysis in the District of Columbia

Full Report

April 2022

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JANE BANCROFT ROBINSON FOUNDATION INC.

BLACK WOMEN THRIVING EAST OF THE RIVER

WHITMAN-WALKER HEALTH
we see you.

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER
GILDA'S CLUB

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Introduction

Racial health disparities are not a new problem in health care or cancer care. Despite cancer innovations in diagnostics and therapeutics and nearly three decades of federal initiatives challenging health disparities, racial health disparities persist in every aspect of cancer care. Black individuals in the United States are disproportionately impacted by cancer, having higher mortality rates than other racial and ethnic groups.[1] According to the 2019 analysis of the American Cancer Society's cancer statistics for African Americans, the 5-year survival rate is lower in Blacks than Whites for every stage of diagnosis of most cancer sites.[2] This is due in part to the undue barriers to quality medical care that Black Americans face. In Washington, District of Columbia (DC), higher incidence and mortality rates are seen for many cancer sites when compared to other parts of the country.[3] For Black women living in DC, specifically in Ward 7 and Ward 8, East of the River, the barriers to care are numerous, with the nearest cancer center being 8 miles away in downtown DC.

Patient navigation has been shown to address health disparities and barriers to quality care for underserved individuals.[4] In addition, patient navigation has been proven to improve timeliness of care access, a critical component impacting the cancer outcomes of Black individuals. Due to these barriers in the accessibility of care, many are often diagnosed after the cancer has metastasized—making treatment more expensive and the outlook for recovery less certain. Based on the Patient Navigation Research Program (PNRP) conducted from 2006–2010 in DC, patient navigation was shown to have positive implications for women diagnosed with breast cancer by decreasing wait times for screening.[5] According to current standards of practice, across the wide variety of professional oncology patient navigators, navigators need to meet standards of ethics, qualifications, knowledge, cultural and linguistic humility, communication and collaboration, advocacy and education, and more, to improve the outcomes of the patients and their families throughout the cancer care continuum.[4]

The Cancer Support Community (CSC) and Whitman-Walker Health (WWH) are committed to improving access to comprehensive, culturally appropriate cancer programs, services, and educational materials. Establishing partnerships with other national advocacy and community organizations is part of their vision for a world where no one faces cancer alone.

Theoretical Underpinnings

Socio-Ecological Model. The Socio-Ecological Model (SEM) developed by Bronfenbrenner[6] grew out of the Social Ecology Perspective.[7] SEM explores and illustrates the relationships between layers of influence on individual health behavior decision making and actions.[8] The model is a series of rings, similar to traditional nesting dolls, with the individual at the center. Each layer progresses outward into the world—Intrapersonal, Interpersonal, Organizational, Community, Policy.[9] SEM provides a structure for understanding multiple influencing factors simultaneously, and a lens for understanding how those systems influence and interact with each other, and how structural systems impact cultural norms for groups. Smedley & Syme[10] stated, "It is unreasonable to expect that people will change their behavior easily when so many forces in the social, cultural, and physical environment conspire against such change." Patient navigation, by its nature, alters the individual's relationship with and improves navigation of the interpersonal, organizational, and even community levels in the SEM.

<u>*Community Landscape Analysis*</u>. A community landscape analysis, sometimes called a community needs assessment, is a crucial component of preliminary data gathering for community-based research or community communication. In a landscape analysis, the goal is to understand and describe the community in all its complexity, its strengths and weaknesses, its networks and needs. The physical and built environment should be incorporated—architecture, topography, walkability, infrastructure, facilities, accessibility, etc. The community demographics and general history should also be gathered. However, a sufficient analysis requires "listening sessions" (qualitative data collection) with as many members and segments of the community as possible. These should include social/economic/political power holders, as well as those who do not hold those resources: organizations and clubs, businesses and residents, informal groups and marginalized groups. Listening and data collection can include individual interviews and focus groups, public forums, observations, needs surveys, and existing quantitative data. In the analysis, the emergent themes should be sifted for community strengths and weaknesses/gaps (within the community), unmet needs, and opportunities for program success and threats/challenges to the program. From this structured and thorough assessment, foundational understanding can inform community communication and research.[11]

<u>*Community-Based Participatory Research*</u>. Community-based participatory research (CBPR) involves equal partnership between researchers and community partners, from study design and priority setting throughout the research process, to determining how best to disseminate the findings. This partnership yields a multifaceted, in-depth, and practical solution while securing sustainable relationships with the target population.[12,13] The result is a research program capable of addressing the complex factors impacting health disparities while also significantly increasing the validity and efficacy of the research program.[14] CBPR is often used with other frameworks and models to examine behavior change.[15] CBPR builds upon traditional public health research methods through involvement of many different perspectives, resources, and skills, and facilitates learning for the researcher as well as the community members[15] to counteract historical obstacles to community partnerships (i.e., skepticism, hostility, etc.).

Together, SEM, community landscape analysis, and the CBPR approach serve as an important lens to elucidate the factors that promote and impede patient navigation in DC communities, particularly in Wards 7 and Ward 8, thereby contributing to health equity in communities of color. Further, these theoretical approaches help community members, community-based organizations, advocacy groups, and funders better understand and advocate for patient navigation services, to identify gaps, and to influence services that partnering organizations provide, making their work more responsive to community needs.[16]

Study Aims

As our study aim was to explore the breadth and depth of cancer patient navigation services in the Washington, DC area, we:

1) Investigated the availability of patient navigation services, including provider types, location, and support offered;
2) Worked to understand the support needs of Black women with cancer living in Ward 7 and Ward 8, East of the River in Washington, DC, and the alignment of patient navigation services to meet those needs.

Methods

Study Design

This pilot study utilized a community engaged, mixed methods experiential design approach (demographic surveys, focus groups and semi-structured individual interviews) to explore participants' (patients/survivors, caregivers, healthcare providers, and community service providers) knowledge, experiences, perceptions and beliefs regarding cancer patient navigation services in Washington, DC.

Human Subjects Protections

This study received Institutional Review Board (IRB) approval by the WCG IRB on 1/10/2022. The Principal Investigators (PIs) and all study team members are certified in the protection of human subjects.

Informed Consent Process

All participants completed an IRB-approved informed consent process prior to their participation in the study. Participants indicated consent by reviewing and signing a consent form, which outlined the purpose of the study, procedures, potential risks/discomforts, potential benefits, confidentiality, and the right to withdraw. Individual consent was obtained in a confidential setting and manner. As this study was deemed a minimal risk study, we requested and were granted a waiver of documentation of consent. All documents were reviewed by our collaborative Partnership Network.

Partnership Network (PN)

This partnership uniquely brings together Cancer Support Community, Inc., Whitman-Walker Health, Inc, the Black Women Thriving East of the River Collaborative, and the Jane Bancroft Robinson Foundation.

Cancer Support Community, Inc.

The Cancer Support Community (CSC) is the largest professionally led nonprofit network of cancer support worldwide. CSC is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC offers the highest quality social and emotional support online, over the phone on their Cancer Support Helpline, and through their local Cancer Support Communities and Gilda's Club Chapters.

Whitman-Walker Health, Inc.

Whitman-Walker Health, Inc. (WWH) has acted as a first responder to the HIV epidemic in Washington, DC's metropolitan community for more than 40 years. WWH is a 501(c)3 nonprofit comprehensive primary care provider with centers of excellence in HIV care and LGBTQ health care. Officially chartered in 1978, WWH has a well-deserved outstanding reputation for high-quality, culturally humble health care. WWH is a Federally Qualified Health Center (FQHC) serving DC's diverse urban community, including those impacted by disparities and barriers to care.

Black Women Thriving East of the River Collaborative

Black Women Thriving East of the River (BWTEotR) is a community collaborative initiated by the Jane Bancroft Robinson Foundation, and seeks to harness the community's assets to transform the lives of families living in the Anacostia area, also referred to as "East of the River," in the District of Columbia. The initiative partners with Black women living in Wards 7 and 8 and the community-based organizations that serve them. At times, these women are referred to as "forgotten," "neglected," and "from the other side of the tracks."[17] The collaborative "strives to address issues of high poverty, chronic diseases, unemployment, and mortality and to shift power and resources to identify solutions and bring about actionable change." BWTEotR works to collaboratively design a series of strategies to change inequitable cancer and health-related career outcomes. By convening the most impacted individuals into issue-specific workgroups on Patient Navigation and Workforce Development, the resulting "road maps" were created to address the root causes of these issues and implement equity-focused solutions in the prioritized community. The goal of BWTEotR is to reduce cancer mortality and create health-related career opportunities for Black women in Wards 7 and 8 by transforming the culture of racially unjust and inequitable systems. Since its launch in August, 2021, BWTEotR has designed a variety of interventions to support the advancement of health outcomes and workforce development opportunities specifically for Black women in Wards 7 and 8.

Jane Bancroft Robinson Foundation

The Jane Bancroft Robinson Foundation (JBRF) was founded in 2011 through the integration of Sibley Memorial Hospital with Johns Hopkins Medical System. JBRF, grounded in the legacy of the United Methodist Church and Sibley Memorial Hospital, supports nonprofit organizations improving the direct health needs and social determinants of health in communities East of the River. JBRF aims to improve the lives of historically underserved residents of Washington, DC's Wards 7 and 8. Their philanthropic approach is designed to increase opportunities for residents to have a voice on the issues that impact their lives, a leadership role in the development of solutions, and decision-making authority to determine how and to whom resources are provided to implement those solutions. One targeted goal of JBRF is to reduce cancer mortality and create health-related career opportunities for Black women in Wards 7 and 8.

Partnership Network Review Process

The Partnership Network (PN) established a collaborative engagement and review process for working together. This engagement included establishing transparency, respect, trust, authenticity, equitability, and consensus on all study aspects. It also built community capacity and accountability for the successful completion of the study. The review process entailed the following:

- Attendance by PN members, co-investigators, and academic researchers at monthly PN collaborative meetings (1.5 hours) to encourage discussion and establish consensus and approval of all study aspects and study documents;
- Implementation of a review period where all research study documents were sent to additional PN members for review, feedback and approval prior to submission;

- Specific emphasis on the structural factors that may promote and impede participant participation. Attention was also given to access issues, cultural and health literacy factors, and processes related to engaging communities of color, specifically in DC communities in Wards 7 and 8.

These strategies are consistent with the literature on CBPR study designs[18-21] regarding the role of the PN and the iterative process necessary to establish priorities, research, solutions, dissemination, and refinement throughout the study period.

Study Population

Participants were recruited from the DC communities, Wards 7 and 8, through our cancer clinic partners (CSC and WWH). We recruited current and past cancer patients, caregivers of cancer patients, cancer healthcare professionals, and community service providers.

Eligibility Criteria

Patient/Survivor Participants a) identify as a Black woman, b) 18 years of age or older, c) can read and understand English, d) are residents of Washington DC Ward 7 or Ward 8 East of the River, and e) are current or past cancer patients.

Caregiver and *Community Service Provider Participants* a) identify as a cancer caregiver or community service provider for a Black cancer patient or survivor who resides in Wards 7 or 8, b) is 18 years of age or older, and c) can read and understand English.

Cancer Healthcare Professional Participants a) are professionally employed as a cancer healthcare provider (e.g., physician, nurse, social worker, patient navigator, financial navigator, nurse navigator, community health worker, etc.) in Washington DC, b) are 18 years of age or older, and c) can read and understand English.

Ineligibility Criteria

Community members who were ineligible, for example, were not yet 18 years of age, were not sufficiently comfortable reading and conversing in English, and/or did not qualify as one of the purposefully sampled groups listed above.

Study Setting

Geographically, the District of Columbia is comprised of eight wards. The most recent census statistics[22,23] indicate that residents in Wards 7 and 8 are twice as likely to live in poverty as the national average (25.1% and 30.4%, respectively, compared to 12.8%). In addition, Wards 7 and 8 residents are 90% and 86% Black, making study accrual feasible for the focus groups and key informant interviews. In addition, Dr. Wallington's previous research[24,25] with this target population specifically in Wards 7 and 8 has shown these communities to be suitable for future cancer prevention interventions.

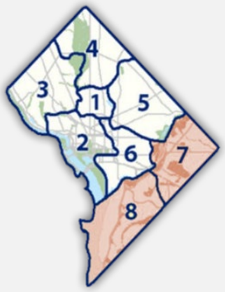

Figure1: DC Wards

Sampling

Purposeful sampling is a well-established practice for qualitative research for the identification and recruitment of information-rich participants related to the community and experiences of interest.[26] As the goal of the sampling was to engage and learn from the variety of stakeholders available, a stratified purposeful sampling strategy was utilized, recruiting from a variety of subgroups within the larger cancer care community for DC Wards 7 and 8.

Recruitment

Participants for the focus groups and key informant individual interviews were recruited through the Partnership Network. Each organization worked collaboratively with each other and utilized their networks to identify participants from the following categories: health care provider (patient navigator), cancer caregiver, community-based organization, cancer survivor. Culturally targeted flyers were designed by CSC, Inc. and were utilized with recruitment email communication. CSC developed the recruitment materials, informed consent documents, and demographic data sheet. All focus group and individual interview materials were also reviewed by the PN, with many of the network members also being representative of the study's target populations (i.e., patient navigators, caregivers, community service providers, cancer community-based organizations, cancer survivors). All focus group and key informant interview participants completed an informed consent process approved by the PN and the IRB and voluntarily chose to participate.

Incentives

All focus group and key informant individual interview participants received a gift card incentive for their participation in the study. In addition, representatives from community-based organizations who assisted with recruitment referrals also received a gift card incentive.

Data Collection

Virtual focus groups and semi-structured individual interviews were conducted using video conference call technology (Zoom Video Communications, Inc., which is a Health Insurance Portability and Accountability Act (HIPAA)-compliant system with end-to-end encryption and optional audio and video recording.)[27] Data collection was guided by IRB-approved focus group and semi-structured individual interview protocols. All data were collected in the spring of 2022. Measures were implemented to ensure that important and relevant considerations were met when conducting focus groups and individual interviews. These considerations included patient characteristics (e.g., diversity), implications for satisfaction with care, quality of life issues, and confidentiality.

Focus group method

We conducted four separate focus groups with patient/survivors, caregivers, community service providers, and healthcare providers/patient navigators to ascertain their patient navigation knowledge, attitudes, and behavior. Each focus group lasted approximately 60–90 minutes and, with the permission of each focus group participant, was recorded via Zoom. The focus group method allows the researcher to draw upon respondents' attitudes, feelings, beliefs, experiences, and reactions within a group setting in an in-depth manner.[28]

Focus group instrument

We developed a semi-structured focus group interview guide. In contrast to the use of a structured focus group guide, this approach enabled focus group facilitators to explore general topics without relying on limited questions defined in advance.[28,29] Having a set of identified topics helps to ensure that participants in each group are asked about the same issues so that responses may be compared. The guide included questions and probes designed to elicit information about patient navigation knowledge, attitudes, barriers, and facilitators.

Key informant individual interview instrument

We conducted seven key informant individual interviews also using a semi-structured interview guide.[30] The interviews engaged various stakeholder groups in Wards 7 and 8. Each interview lasted approximately 30–45 minutes and, with the permission of each interviewee, was recorded via Zoom. Key informant interviews allow in-depth exploration, are inexpensive and fairly simple to conduct, and provide interviewer flexibility.[30]

Focus group and individual interview protocol review

The focus group and key informant individual interview guide was vetted for cultural, linguistic, and health literacy appropriateness by the study team and the PN members. The guide was also sent for review by other PN members, many of whom represent the target populations.

Data Analysis

Focus group sessions and key informant interviews were digitally recorded, with participant consent, and transcribed utilizing the Zoom iCloud transcription platform feature. NVivo 12,[31] a qualitative and computerized informatics tool,[32] was used to import transcribed data and set qualitative databases. It has features that allows one to drill down into the data by explicating chunks of texts and uncovering subtle connections in ways that are simply not possible manually. This informatics tool helps link emerging themes back to the original text that supports them, rigorously justifying findings with evidence. Researchers independently conducted their own NVivo analyses to ensure that database development, data analysis, and interpretive analysis are objective.

During each analysis, data were coded from transcripts using a process of open, axial, and selective coding using NVivo 12 software.[32] Drs. Wallington and Coker-Appiah independently developed coding schemes by identifying, classifying, and labeling the primary patterns in the transcripts. During open coding, the constant comparative approach[33] was used to group the codes into categories, where each category is considered a unit of analysis, and themes were identified. Axial coding was then applied to explore the inter-relationship of categories. The frequency and consistency in which participants indicate categories in the transcripts were used to provide credibility for these categories. Intercoder reliability between the investigators were assessed using Kappa statistics (in NVivo 12) and any disagreements were resolved by consensus of an additional investigator.

Results

Participant Demographic Data

We invited 37 individuals to participate in the study, with 32 completing the study. There were 25 focus group participants (8 patients/survivors, 6 caregivers, 5 healthcare providers, and 6 community service providers), and 7 key informant interview participants (3 patient/survivors, 3 caregivers, and 1 healthcare provider). Nearly all participants were Black or African American, non-Hispanic women. Patient/survivor participants were approximately 60 years of age on average, while healthcare providers and community service providers were younger. Details are in Tables 1 and 2, below.

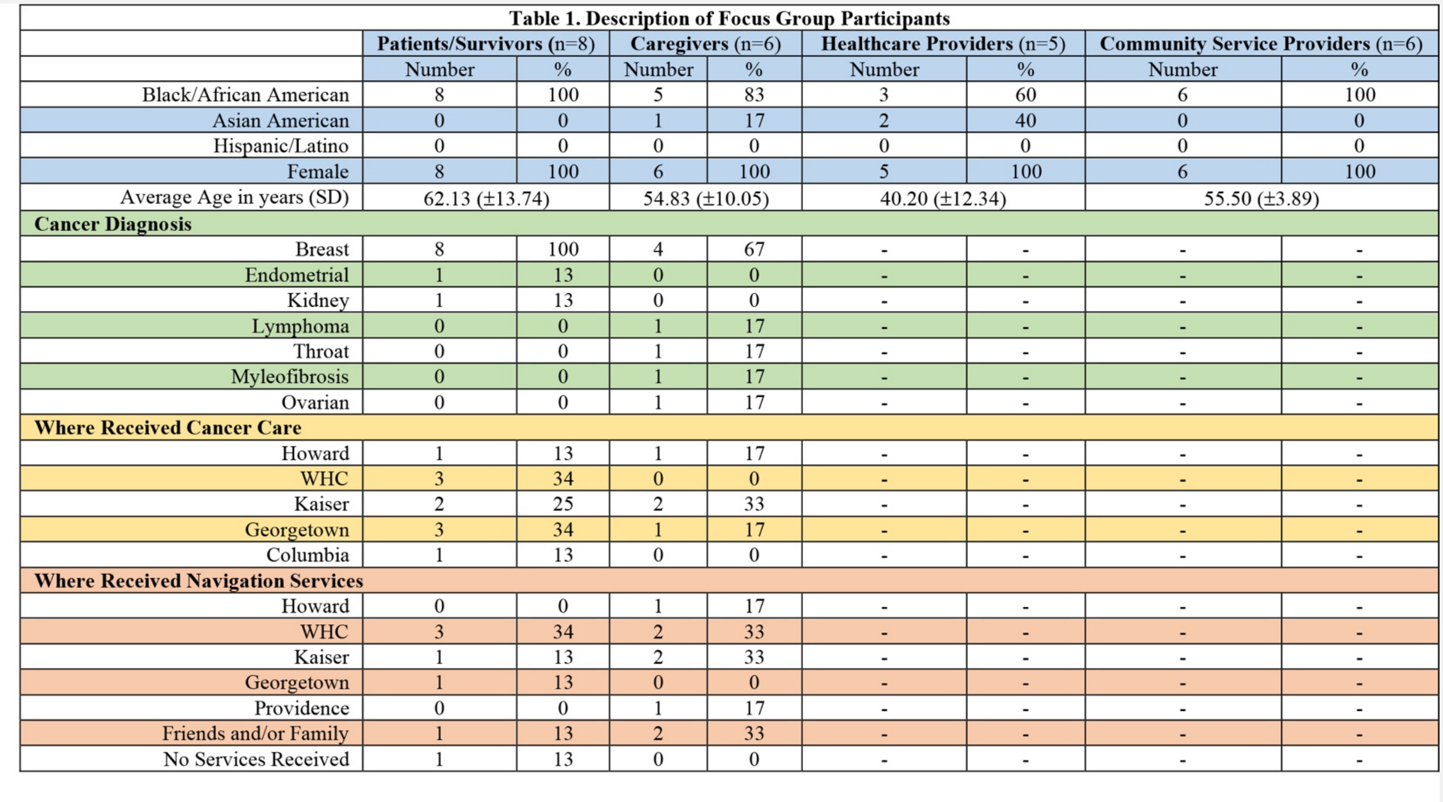

Table 1. Description of Focus Group Participants

	Patients/Survivors (n=8)		**Caregivers** (n=6)		**Healthcare Providers** (n=5)		**Community Service Providers** (n=6)	
	Number	%	Number	%	Number	%	Number	%
Black/African American	8	100	5	83	3	60	6	100
Asian American	0	0	1	17	2	40	0	0
Hispanic/Latino	0	0	0	0	0	0	0	0
Female	8	100	6	100	5	100	6	100
Average Age in years (SD)	62.13 (±13.74)		54.83 (±10.05)		40.20 (±12.34)		55.50 (±3.89)	
Cancer Diagnosis								
Breast	8	100	4	67	-	-	-	-
Endometrial	1	13	0	0	-	-	-	-
Kidney	1	13	0	0	-	-	-	-
Lymphoma	0	0	1	17	-	-	-	-
Throat	0	0	1	17	-	-	-	-
Myleofibrosis	0	0	1	17	-	-	-	-
Ovarian	0	0	1	17	-	-	-	-
Where Received Cancer Care								
Howard	1	13	1	17	-	-	-	-
WHC	3	34	0	0	-	-	-	-
Kaiser	2	25	2	33	-	-	-	-
Georgetown	3	34	1	17	-	-	-	-
Columbia	1	13	0	0	-	-	-	-
Where Received Navigation Services								
Howard	0	0	1	17	-	-	-	-
WHC	3	34	2	33	-	-	-	-
Kaiser	1	13	2	33	-	-	-	-
Georgetown	1	13	0	0	-	-	-	-
Providence	0	0	1	17	-	-	-	-
Friends and/or Family	1	13	2	33	-	-	-	-
No Services Received	1	13	0	0	-	-	-	-

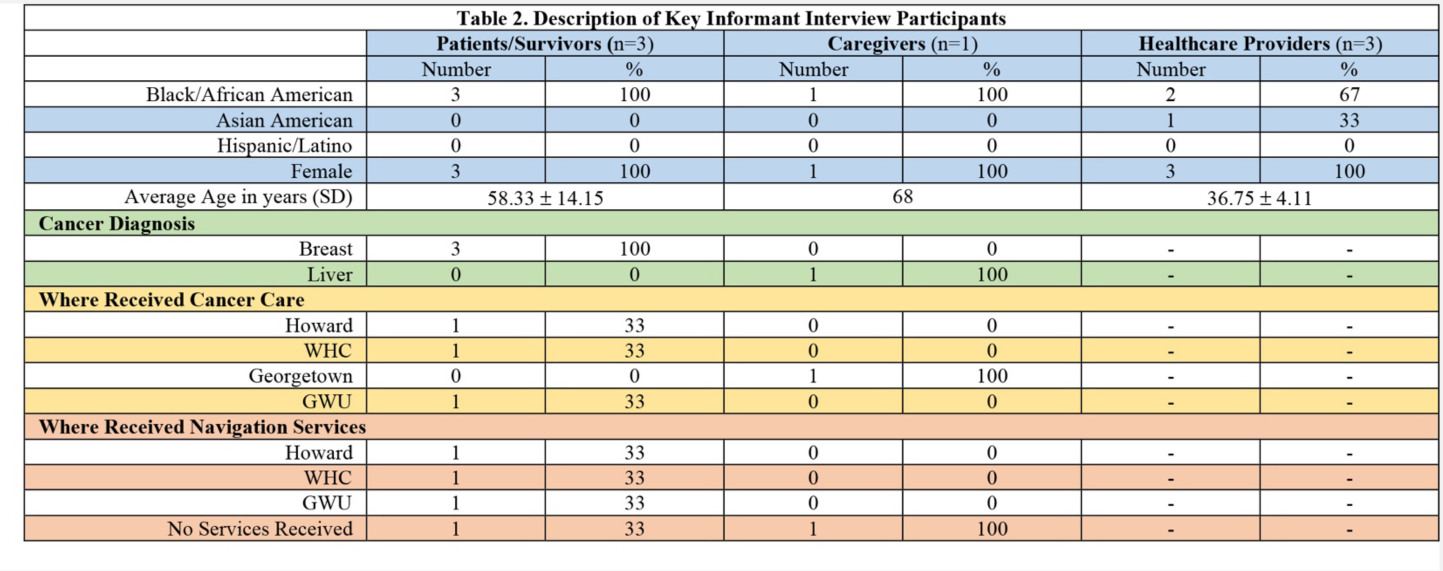

Table 2. Description of Key Informant Interview Participants

	Patients/Survivors (n=3)		**Caregivers** (n=1)		**Healthcare Providers** (n=3)	
	Number	%	Number	%	Number	%
Black/African American	3	100	1	100	2	67
Asian American	0	0	0	0	1	33
Hispanic/Latino	0	0	0	0	0	0
Female	3	100	1	100	3	100
Average Age in years (SD)	58.33 ± 14.15		68		36.75 ± 4.11	
Cancer Diagnosis						
Breast	3	100	0	0	-	-
Liver	0	0	1	100	-	-
Where Received Cancer Care						
Howard	1	33	0	0	-	-
WHC	1	33	0	0	-	-
Georgetown	0	0	1	100	-	-
GWU	1	33	0	0	-	-
Where Received Navigation Services						
Howard	1	33	0	0	-	-
WHC	1	33	0	0	-	-
GWU	1	33	0	0	-	-
No Services Received	1	33	1	100	-	-

Major Themes/Subthemes

Analysis of the focus group and key informant individual interview data resulted in the emergence of eight major themes, and several subthemes, which included: 1) *navigator knowledge and awareness*; 2) *access to patient navigation services*; 3) *interactions with healthcare providers*; 4) *team approach*; 5) *cultural implications*; 6) *barriers and needs* (for patients and caregivers, and for providers); 7) *impact of COVID-19 on patient experiences*; and 8) *provider commitment to navigation services*.

Theme 1:Navigator Knowledge and Awareness

Definitions:

Various definitions were given by respondents according to their understanding of what patient navigator means. When asked about what they felt patient navigation could be, the majority mentioned guidance and leading the patient through the processes to get the best results from their cancer treatment experience, *"I think of someone guiding you through the treatment process."* They hold the patient's hand and take them step-by-step through the process, *"…they kept me up on all of my appointments and things of that nature, and, like you said, what the next step was in terms of how we would navigate through this process."*

Many respondents spoke about patient navigation as a source of information regarding resources available to cancer patients and their caregivers. They shared that often, when patients are first diagnosed with cancer, they struggle to retain information shared by their doctors at that moment. They suggested that this is an important role of patient navigation: to assist patients with the information they may have missed during their doctor's visit, *"…sometimes when you get information from the doctor, you hear it and you don't hear it. So the patient navigator is there with you. They'll hold your hand and then later we can go back and like discuss it to make you [understand]."*

Some defined patient navigation as someone to provide emotional support for the cancer patient. One participant stated, *"Someone to give you support when needed … giving them support whatever they're going through."* For others, patient navigation was defined as a guide through the process. For example, *"Help is on the way, that you have a support that's actually going to lead you through whatever process you need to go through."*

Resource provision is another factor according to some respondents. They may assist a patient with access to resources, such as transportation or applying for financial aid, when necessary. One participant shared, *"…also the patient navigator provides resources like if you need additional support or resources, like you know, transportation stipends or any other things [needed] … to go through the journey and make you comfortable."*

Navigator Awareness:

There were respondents who acknowledged not knowing what patient navigation is. This trend was seen across all of the groups in the study. One cancer survivor shared, *"…when I was going through cancer, I have never heard of patient navigation."* One of the caregivers also commented that they had not encountered the term patient navigator, *"…when you say navigation, I didn't know what y'all was talking about."* Some providers expressed the concern that some patients and their caregivers might not view navigators as necessary in the journey, that they might not understand their role. One provider expressed:

> *"…sometimes I think patients don't understand my role…I'm meeting with patients so soon after diagnosis, you know they're getting their footing and adjusting and they might not recognize all of the psychosocial impacts of this diagnosis yet. That may make it harder to understand why would [they] need a social worker?"*

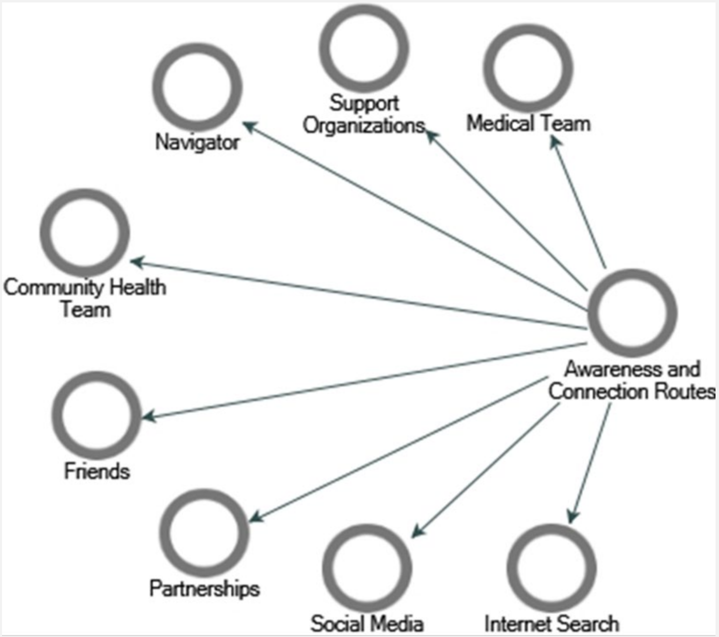

Figure 2: Awareness and Connections Routes

Other respondents knew exactly what a patient navigator is and what their role is in a patient's journey. One caregiver said, *"Yes, I've heard of it."* Various respondents who were providers also stated that the patients and the doctors they work with understand what their role is when dealing with cancer patients. One of the providers commented about patients' awareness level:

> *"I do think they understand the role that I play, because most families and patients, they understand that they can't talk to the doctor every five minutes with every concern that may come up. … So I feel like…they think I'm like the gatekeeper, which I am. I can tell all my patients [I'm like] Dr So-and-So's right hand…"*

Among our participants, there were just about as many who had heard the term "patient navigator" and understood their role as those who did not.

Theme 2: Access to Patient Navigation Services

Referrals to Navigator Services:

There were a variety of ways that participants reported patients hearing about navigation service providers and the significance of their involvement in the care process. One of the ways mentioned is through the doctors or surgeons. When a patient is first diagnosed, a doctor may recommend the services of a patient navigator to a patient. Some patient respondents indicated that this was the way they were connected to patient navigators, *"I found out from the doctor."* A different respondent stated, *"I actually have a friend whose daughter was diagnosed with breast cancer and her physician handed her a packet of information and inside, there was a Smith Center pamphlet and she said, 'this is a good organization, you should connect with them,'…and so that's how they find out…"* The providers also mentioned that the patients will most likely get connected to a patient navigator through their medical team or their social workers, *"I'm sure from their oncologist…those are the ways that I know that they find out about (the) nurse."*

Internet searches were mentioned by one participant as a way that patients and caregivers receive information about patient navigator services. They shared, *"Some people find us just by, you know, getting on the internet and googling us and then finding out that we have patient navigation…"*

There are also patients who get connected through word of mouth or referrals from partnerships formed among medical providers and social work institutions. One of the providers mentioned this as a major way in which they get connected to cancer patients, *"...she signed up for a … home health aide … and somehow or other she got connected with me…"* A different provider also shared a similar experience, *"...we also partner with a lot of the local hospitals and doctors, you know some of the doctors around and so some people just tell people…."*

There are instances where patients connect to patient navigators through support organizations, such as Kaiser Permanente, according to one of the caregivers who was connected through that channel: *"Well, I think, in my wife's case, Kaiser Permanente assigned someone to help in that process…"* Also, through the cancer support helpline, patients were connected to patient navigator services, as well as by getting information from friends.

Most respondents described receiving information from their medical team—doctors, nurses, social workers, and the oncology team in general.

Navigator Services Offered:

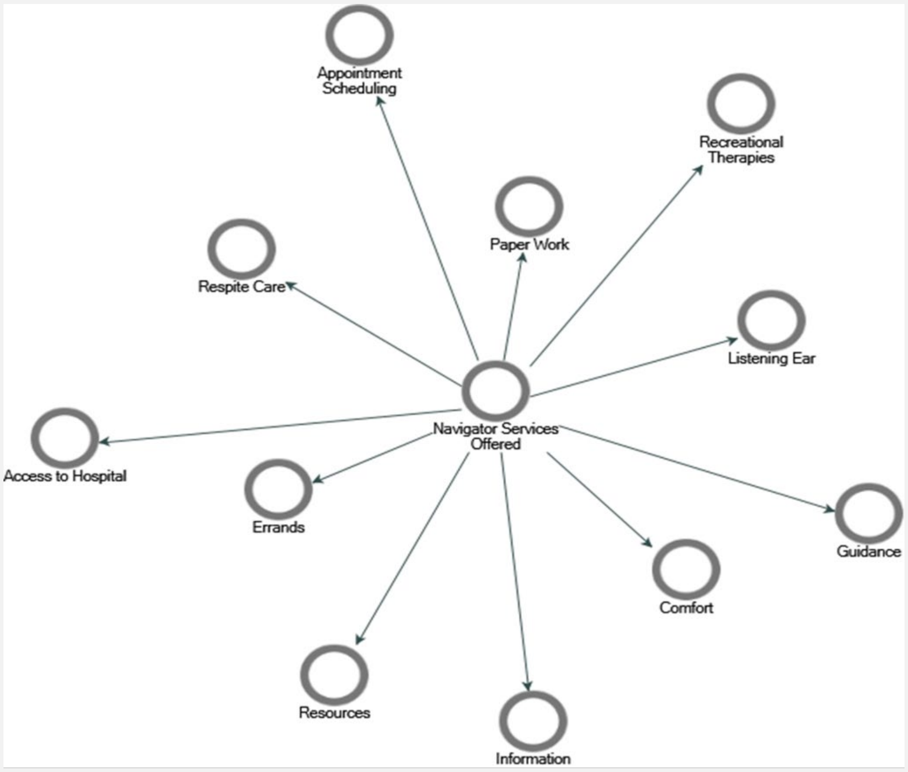

Figure 3: Navigator Services

The most commonly mentioned service across the respondent groups was providing information to enable patients and their families to navigate through the processes more easily. This included information provided on various aspects of the treatment plan, including cost estimates, nutrition, mental health/support groups, and the resources that are available, such as transportation and financial aid programs. One respondent stated, *"If I needed support groups, she informed me of all kinds of focus groups or my cancer things that I didn't know that maybe (the) doctor didn't tell me about it…"* Another commented, *"...she kind of like guided me what steps to take, what I wanted to do, if I needed help with transportation."*

There were providers who described having shared information concerning wigs and bras with patients to help make their experience more comfortable, *"...some patient navigators will tell you if you have to have reconstructive surgery about … where to get bras from or the bra referral."* Participants discussed receiving information for supporting mental health, and some respondents also talked about receiving information concerning genetic testing, which led to their opting to be tested.

Respite care is a service that some of the providers reported providing for their patients. Respite care is taking over the care of the patient for short periods of time to allow the family to take a break, *"… I'm an outlet to let her family breathe for a while and let me take up the slack for a little bit."* Running of errands was also mentioned by some respondents as something providers offer their patients. One of the providers shared, *"...she'd like to eat and I try my best to … find it for her. … I just want you to enjoy your life to the fullest while you can, simple as that."* One of the respondents who had been on the receiving end of these services also stated, *"If I need anything from the store, they would go to the grocery store for me, anything that I needed, all I had to do is ask."*

Processing paperwork, taking patients to their hospital appointments, and scheduling appointments were also some of the services the patient navigators offered patients. In addition, they offered emotional support through lending an ear to patients, letting them vent, offering comforting words, and forming bonds with them, *"We actually developed a friendship out of that … she was there for me to make sure that I was comforted…"*

Variability of Receiving Navigation Services:

When the respondents were asked if the patient navigator services were part of their experience, there were those who indicated they had received navigation services, and those who had not. Some patients were not connected with a patient navigator, but did receive support from other sources including support groups, family, friends, and other support organizations, such as Kaiser: *"I was gonna say I also have a support group that was birthed out of Kaiser…"* There were those who described having prior experience with cancer with their family members. This, according those participants, made them more equipped than an average cancer patient, and they were able to better maneuver their way through the recovery process. One of these patient respondents stated, *"….my father had cancer, so I used to take him back and forth for his support, so I guess that was…kind of self-care…because I didn't take people to appointments with me…"* There are caregivers who did not get assistance from a service navigator as well, *"My first time with it, I didn't have a patient navigator with my daughter."*

There were also caregivers and patients who described having received the services of a patient navigator. They were connected through various means, including the medical team right after diagnosis. One caregiver shared, *"Yes, my husband was assigned a patient navigator at Howard hospital, which was a lot of help…"* One patient respondent said, *"as soon as I was diagnosed, I was assigned a navigator…"*

There were almost as many respondents who received navigator services as those that did not, but many received support from various other sources.

Access Period:

Some participants shared that they were able to connect with patient navigation services immediately after their diagnosis, while others were connected after some time, and still others after their surgeries. One patient who was connected immediately to services commented, *"…when I first met my surgeon, I was introduced to the navigator then, at the very beginning…"* A caregiver also shared, "*I think in my wife's case, as I recall, was actually at the beginning stage, following the diagnosis, because that's when she was assigned a nutritionist as well…"*

Regarding the longevity of access to patient navigation services, different responses were shared by the providers. Some shared that patient navigation services were offered for as long as a patient needed them, "*I'm available … to patients once they're done with their six months that I work with them."*

For some navigators, if the patients were still going in to see the doctor for follow-up visits, including during their survivorship period, they were able to access the services, *"…as long as the patient is still following up with the physician* *in survivorship, we're still there for them, so they can come to us at any point."* However, in other cases, if there was no more active follow-up, especially with the doctors, then some navigators terminated the navigation services and referred them to other services, *"…if somebody is no longer following with the breast surgery team, then my role as a navigator might look more like referring to outside community partners…"* Also, there were those who reported that they offered the services until the patient stopped receiving active care from the hospital. This can also refer to when the patient passes away or when they are admitted to a hospice facility, *"…our patient navigation from a GI standpoint, kind of ends at hospice or till the patient is deceased."*

Proactive Navigation:

Some patient navigators described employing proactive means to ensure patients received the services they needed. These proactive measures applied particularly in cases where patients were hesitant, secretive, and/or unwilling to disclose their needs to the navigator. They reported the need to employ their skills to extract more information from patients to connect them with services that could make their cancer treatment more bearable. One of the providers stated:

> *"I just want to mention a lot of times patients will not always let you know that there is a need. Sometimes we have to be almost like a detective or an investigative reporter, to try to extract that out of the patient, just to let them know that it is okay. You know it's okay, if you need help. It is OK. Sometimes we just like to stress that to make them feel comfortable. And these resources are here to help you get through this part of your journey."*

Electronic Medical Records:

Some providers reported having access to EMR systems, which assisted with documenting and tracking patient information, *"Yes, we have an EMR system and everything is documented in that system."* Other providers mentioned using other recording systems, such as specific forms, to complete tasks such as scheduling, *"If we're scheduling transportation, or something we can just fill out what's called a power form in the record."* They also highlighted the importance of writing notes when they were not able to complete elaborate documentation, *"…if I'm having a more extensive meeting, I will actually write out a note. But yes, everything should be documented."*

Referral Process:

When it comes to the process of referring patients from one department to another, different providers involved in the discussion mentioned some common processes that they follow. For most of them, screening was the first step, including asking questions concerning housing and finances. This helps gauge the level of assistance that each patient requires. Following screening, individual assessments are completed with patients. This step helps navigators confirm services that patients truly need:

> *"I also am meeting with all patients who have a new cancer diagnosis. I'm completing an assessment, as well as distress screening, which [other participant] emphasized the importance of and me finding out the needs in that way. So, sort of referring people based on the outcomes of that, those assessments."*

Some provider participants also shared using other departments to help with the patient referral process, *"I'll just send usually send emails and that's how I get assistance from the nurse navigator or the social workers in our social work office."*

They reported making patient referrals to relevant departments through the use of email communication as well as through the medical record system.

Theme 3: Interactions with Healthcare Providers

Connections between providers:

The patient navigators and other professionals who engage in providing navigation services for patients reported having various ways in which they connect with other providers in other geographic areas. One way of connecting is through annual summits where navigators meet from various locations and are able to network and share ideas and knowledge concerning patient care and resources. One of the provider respondents said:

> *"Oncology Nurse Navigation Summit and that's held every year. We would meet in person, but due to COVID, the last two years, it's been virtual and it's actually taking place again next month. That's an excellent opportunity for networking and collaboration. And also, just to get an idea of how navigation is done at other facilities and other practices within the US."*

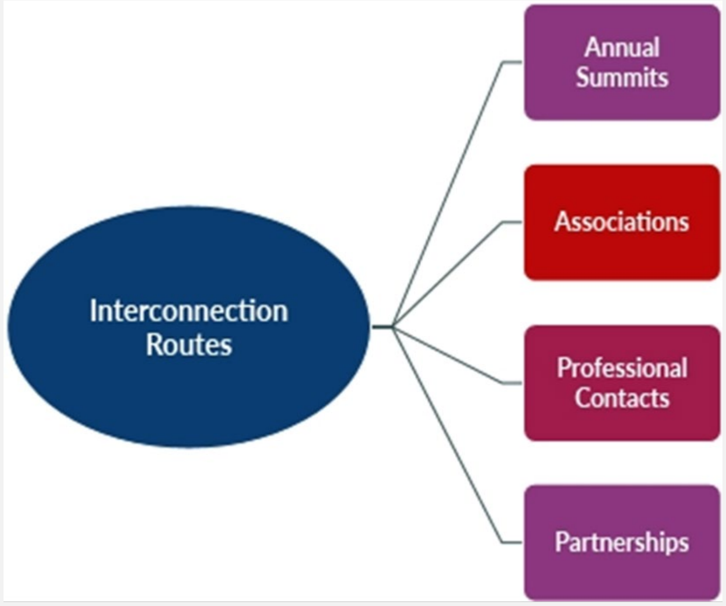

Figure 4: Interconnected Routes

One of the providers also mentioned being a part of professional associations and bodies where different providers meet and share resources and ideas to help improve the services they offer to cancer patients: *"I'm a member of the Association of Oncology Social Work, which is a national organization which allows people to connect, look for resources and help with challenges. So that certainly is helpful."*

There were some providers who described having worked with various organizations from where they have held on to contacts and networks,

> *"…then within DC, I'm lucky enough to partner with a number of social workers and other providers just from having worked at a few different places, you know, being able to contact former colleagues, to find out if they have any suggestions or resources…"*

There are partnerships that have been established that also connect facilitators who then collaborate and offer support to one another when needed:

> *"…we have partnerships across the institutions in DC, so I feel like there's just so many people that if I'm looking for support or help, they're just countless numbers of people and they're willing to lend a helping hand…."*

Internal Collaborations: Patient navigators mentioned quite a number of people with whom they collaborate to assist with making patients' experiences seamless and less stressful. Most of the individuals with whom they work are on the medical team, such as the doctors, surgeons, pharmacy team and nutritionists: *"I definitely collaborate a lot with the doctor. I feel* *like the doctor's right hand, for sure."* Another navigator also shared, *"I've been working with the endocrinologist and dietitians as well."*

Nurse navigators were mentioned by some of the respondents as people they collaborate with internally, as well as mental health providers, such as psychiatrists and psychologists, *"…further, also psychiatry and a psychologist … sometimes are involved in our patients' care, so there's certainly a lot of internal collaboration…"*

Home health providers are also involved in some cases, and therefore collaborate with the patient navigators. Administrative staff, such as front desk personnel, are also sometimes involved in patient navigation, especially in smaller establishments, *"…front desk staff, everybody involved in the patient's care, as well as the nurse navigator and executive assistant…"*

Transportation and delivery service providers and companies such as Uber and Lyft were also mentioned as part of the collaboration team, and played roles in helping patients receive efficient cancer-related care. They often help with deliveries to patients as well as with transportation: *"we have a team called CRS and they're really, they help with like transportation and like finding transportation based on people's insurance and I work with them a lot as well."*

Preferred Information Provider:

Participants shared their opinions regarding which individuals they feel are best equipped to offer information concerning cancer care and available resources. Some felt that the best person is a loved one, *"…close family member … if someone is walking this journey with you. I think, [they] can be a good person to explain to you what a patient navigator is."* A different respondent also commented, *"…talk to the children, some people don't, I guess they don't want to worry the children, but I mean talk to their children, a close family member, sister, brother, husband."*

One of the respondents stated that the doctor is the best person to provide information to patients because they are better equipped to give explanations in a patient manner, *"Yes, I think [the doctor] should be the one to talk to him or her because they could be patient with them and let them know what's going on."*

Having someone who has previously dealt with cancer, directly or indirectly, or a religious figure relay information to the patient were other suggestions that were offered by one of the community service providers. They shared, *"Someone that's already … been through it, or maybe their pastor."*

Other suggestions included therapists, social workers, or nurses at the hospital, *"Better in my experience, sometimes I think hearing it from the nurse or the nursing staff or some others. It is heard a little bit better than coming from the doctor…"*

Cancer Care Team

From the discussions, it was established that there are respondents who have walked the cancer journey alone, with only the support they receive from the medical team, and there are those who also had strong family support systems in place during that period. Therefore, the cancer team for every patient varies, and includes some combination of the medical team, social work and/or mental health support, religious networks, and family and friend networks. Other sources of support for the cancer patients included organizations that provide transportation services such as Uber and Lyft. There are patients who received support from friends, who walked with them throughout the process and accompanied them to appointments and acted as their peer navigators. It was shared that there are cancer patients who also strive to show compassion to fellow cancer patients and give them encouragement during their treatment process by sharing their personal experiences: *"…a breast patient who decided to become a volunteer in my department. So patients would come down and when they were in the waiting room, she would kind of talk to them about her experiences and then the patients would share their experiences with her."*

Word Cloud 1: Cancer Care Team

All of these individuals and organizations worked together to create the team that provided support for patients, based upon their circumstances and needs.

Team Roles

Respondents discussed the roles of various members of the cancer care team as well as how they vary from one institution to the next. The first role is providing information to the cancer patients and educating them about cancer, *"…one of our goals is, we provide a lot of educational information…"* This information is provided to assist patients with navigating the system to reduce stress levels.

Another role is sharing resources with patients to help alleviate obstacles, such as financial strain, *"…we do have the financial navigator which has been extremely helpful with insurance issues…"* They also provide psychosocial resources, such as mental health information: *"…they have also been able to provide some psychosocial resources for a lot of our patients. That's another challenging area, because most mental health care providers do not accept insurance. They've been able to help with that resource."*

They also provide logistical support, such as appointment scheduling for patients, to ensure they stay on track, *"…I'm responsible for tracking patients and ensuring they're coming in for surgery follow ups…"*Additional roles involved making patient referrals to other departments for care and making reminder calls to ensure that patients who may be overwhelmed with their care receive adequate assistance.

Helpful Navigator Assistance

Providing patients with a support system was identified as a very useful resource, *"One of the most important things, for me, when I was going to do my cancer battle, is just knowing that you'd have a support system there that will be able to aide you."* Another participant commented similarly:

> *"…just having that person there is, from what I've seen and what people have shared back, just knowing that you have someone else in your corner … knowing that someone else is there that cares and can help you, I think just makes what's a really, really hard, hard moment in your life, a little bit brighter, a little bit easier, because you have that support."*

Having someone to guide and direct patients on the processes and steps to take was also identified as very helpful. A survivor participant offered, *"…[they] will be able to direct you to the resources that will be able to assist you. So that was most important to me, when I was going through my battle."*

Receiving information from patient navigators concerning resources and steps that a patient should take was valued by patients. This was highlighted by one of the community service providers, who had an opportunity to care for a cancer patient and observed how appreciative the patient was of her assistance and the information she provided:

> *"…She tells everybody on a daily basis. I hear her talking to people on the phone and she just tells these people, 'Oh my god! I'm just so blessed. I'm just so thankful that I got this young lady that's here to help me. She's just such a blessing to me. Oh, I'm just so happy.' She says this all day long and it just makes me feel so good."*

Showing care and providing comfort were also appreciated by the patients. One community service provider shared,

> *"…That person was always there. She referred to everyone, but particularly the navigator that was sort of assigned to her as her team. She felt very comforted by that. It was actually a great comfort to me as well, because I was not living in the same city. Just knowing that there was someone..."*

Another community service provider commented similarly:

> *"…Make sure she gets what she needs. If she says she's cold, make sure we put a heater in the room with her. And try to be more of a comfort. Because I'm not a nurse, but you know, whatever she may need and ask for, which isn't really much, but just for her to know that someone does care and can be there if need be…"*

Theme 4: Team Approach

Team work was mentioned as one of the ways that the cancer care providers approach their work. One provider may not be equipped with certain skills, yet they are able to reach out to their skilled counterparts to receive the assistance they need for patient care. One of the providers shared:

> *"That's why they're going to provide that assistance, and then the social work office, with [other participant], who's able to have connections to other resources … and [we] worked in tandem, in a teamwork effort for me."*

A different provider also agreed with the fact that team work is necessary to execute their roles, *"I'll jump in, what's that saying? Teamwork makes the dream work."* Team work makes their work run efficiently to the benefit of the patient.

Since the onset of the COVID-19 pandemic, a lot has changed, especially when it comes to ways in which care is provided for patients. According to one of the providers, there is a need to think outside the box if one is to provide effective care for patients during this challenging time, *"…normalcy has gone out the window, especially since we're in COVID, because you know, this is a new norm, so you have to think out of the box…"* Therefore, providers need to find creative ways to deliver services to their patients as seamlessly as possible. They have had to tap into other resources and even use non-traditional approaches to ensure the patients are well cared for in terms of cancer care:

> *"You have to be able to identify resources and they may not be your traditional resources. I'm in a sorority as well. So right, you may have to tap into that sorority sister. I've done that for patients before like when the Uber transportation never showed up. I'm using my own Uber account to get [the patient] home, but I'm willing to do that…"*

Theme 5: Cultural Implications

According to the participants, there are instances where culture has played a role in a patient's cancer treatment journey. In an instance where culture was a factor, it was related to patients not being offered appropriate cancer care treatment plans, and were instead offered less-effective options. One of the caregiver respondents stated:

> *"…implicit bias, yes, the answer is yes, yes. That's why we had advocated as hard we did. And what was interesting is the physicians in and of themselves, I think, are fairly decent and what have you. But in terms of the precise, appropriate treatment regimen, that's the part we had to argue. … Because my daughter was able to discern this information and maybe discount 70% of information as not being valid to my wife's case, she was able to politely persuade them that a more aggressive form of treatment would be appropriate. And so, yes, there was some type of implicit bias experienced in that situation."*

A different caregiver also had similar complaints and shared dissatisfaction with the manner in which the doctor treated her loved one's case and did not offer her aggressive care, as was needed:

> *"With my mom, she's a stage four. She wanted to be aggressive, and the doctor was like 'I'm not sure because of your age. I'm not sure you're a good candidate,' and she said 'well, I'm stronger than you think I am.' And, then 16 weeks into laser, 'I'm surprised you're still here.' And I was surprised that a doctor would actually say that."*

Most of the respondents, however, did not feel like there were any cultural implications regarding the care that was provided to cancer patients. For example, *"I didn't notice it in, I don't know, it may have been at the hospital that my husband's at was a lot of minority and people of color, so maybe that was the distinction."* Another respondent also shared similar sentiments, *"Oh, my mother had a good doctor and a good surgeon."* In general, there were more positive experiences compared to negative experiences related to cultural bias.

Theme 6: Barriers and Needs

There were various barriers and needs that were mentioned across the four categories of participants with regard to the nature of care that cancer patients receive in Washington, DC. Both patients and providers face challenges, which affect the proper provision of care for cancer patients.

Patients and Caregivers:

Mental health issues of both patients and caregivers were identified as one of the major challenges. Patients experience emotional strain due to their own health condition, *"…just having the diagnosis, there's a lot of depression, anger, anxiety, that just feeling overwhelmed. They're not really comfortable letting their family and friends know what they're really feeling."* And the caregiver also goes through emotional stress due to the fact that their loved one is unwell and also the effort that goes into the caregiving process. One of the caregivers shared, *"…it can be very stressful on a caregiver, especially if it is your family member, especially like being your mother or you know, a close-knit family member…"* There were patients who have had problems accessing mental health services due to insurance restrictions, which serves as a barrier to their care: *"…they have also been able to provide some psychosocial and resources for a lot of our patients, because that's another challenging area because most mental health care providers do not accept insurance…"* According to a provider, the pandemic has also exacerbated the situation and hindered some patients from accessing mental health services, *"…That patient I spoke with yesterday said she was on a really long waitlist and she really needs to see a psychiatrist. It's difficult."*

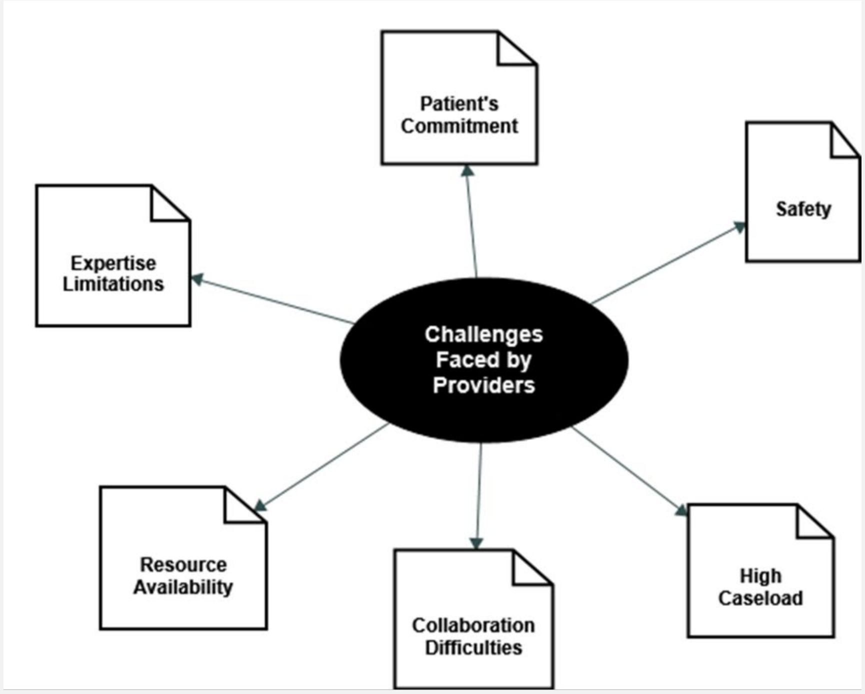

Figure 6: Provider Challenges

Financial difficulties are also common among the cancer patients. Some patients face financial strain due to the cost of cancer care or because of insurance restrictions, *"The number one problem I encounter as a social worker working with primarily low-income patients, is that they just can't afford the mental health…"* The financial problems in turn affect housing as well, *"And you know the financial need as well, which also lends itself to the housing issue."*

Housing has been identified as a big issue that's affecting most of the low-income patients. Most of them are living in crowded households and receiving affordable housing is not easy due to waitlists, *"I think the number one thing for me is housing concerns, there's, just as [Name Redacted] mentioned, a dearth of affordable housing options to tap into resources, there's often waitlists and you know."*

One of the respondents also spoke of being dropped from their navigation team, *"…my navigation team, they disappeared after a while. I have not heard from them."*

Providers:

The providers raised concerns regarding the level of patient commitment, especially when they have received information and resources to help them secure better care. The following comment highlights this challenge: *"I can sometimes put it in post or mail and the next week, when I talk to them, 'Oh I didn't call.' so it's like that frustrates me."* A similar reflection:

> *"…it also depends on the motivation of the patient, as I would say, you can lead the horse to water, but you can't make it drink, yeah, so you know you can give them all the resources in the world, but it's ultimately up to them to take advantage of it…"*

There were concerns about the high caseloads that patient navigators sometimes have to manage. This may lead to some of the patients being dropped without the provider's knowledge, *"…there are three social workers to thousands of patients. So, it can be very difficult to kind of keep track of everyone and what's going on with everyone. And I think that's, that's a huge barrier for us…"*

The resources that are available are not adequate to meets patients' needs, thus resulting in a hindrance to the services being provided to the cancer patients, as shared by some of the provider respondents. One resource that appears to be lacking, is human resources necessary to support cancer patients as they navigate their treatment process:

> *"…at GW, one of the main draws for me was that I was going to primarily be providing mental health and emotional support, and no longer helping with some of the barriers to care that are practical in nature, transportation, finances, etc. And so, then when they eliminated that program and they no longer had the lay navigators, suddenly the two social workers, myself and another colleague, were tasked with those responsibilities, in addition to our other core priorities."*

Having patient navigators who are not skilled enough to provide some of the advanced care that is needed for cancer patients was mentioned by one of the respondents as a barrier as well:

> *"Around any kind of medical information, they're not qualified to provide that. When patients are navigating complex, often advanced cancer diagnoses, they need people who can really, you know, join with them and explain and reiterate what the doctors are saying, versus people who maybe aren't able to assist with some of those more nuanced medical things…"*

Patient navigators described the challenge of colleagues on the cancer care team not always understanding the full range of what they do and how it fits in the patient's care: *"I think sometimes medical providers' focus is treating the cancer. It makes perfect sense that their main focus is not the psychosocial impact of cancer. While I think providers that I've worked with over the years do understand my role to some extent, they might not understand what the patients are really needing, and so that creates a barrier to referral and collaboration sometimes."*

Perceived safety was cited by one of the providers as something that may hinder a navigator from serving patients from certain areas in DC, *"The area is not a safe area."*

Theme 7: Impact of COVID-19 on Patient Experiences

The COVID-19 pandemic affected the experiences of cancer patients in various ways. One of the ways is that it caused a lot of mental stress. It brought fear among the patients as people became skeptical about going into the hospital for care. One of the community stakeholders shared, *"I think it has impacted people. … Everyone was basically afraid to go out. We didn't know how COVID was transmitted, and you know we're wearing gloves and we're wiping down all of our stuff."* Many things were canceled, which added to the stress, and there were delays in terms of vaccine availability for cancer patients: *"…and then for a long time, they couldn't get vaccinated. I know in DC, that cancer was not on the priority. It was on the list, but it was lower. So cancer patients weren't able to get vaccinated, which was adding more stress..."*

Another impact brought by the COVID-19 pandemic was the heightened awareness that people needed to get checkups and regular screenings, *"Since we have COVID, it seems like everybody been going to get themselves checked."* Combined with the backlog of non-emergency care that was postponed during the early months of the pandemic, these have led to challenges in appointment times, waits, and resources.

Virtual appointments have also come out of restrictions related to COVID, *"And then they did most of the appointments on virtual … you still were able to actually see and talk to your doctor personally, one-on-one, face-to-face on virtual."* In-home services were also incorporated in some instances, according to one of the community service provider respondents, *"I noticed that they had like the nurses … that come out to visit some of the ones that cannot get to the hospital as far as giving them the COVID shots or something like that, somebody came out, and gave it to them."*

Also, due to pandemic restrictions, the patient support system was affected in terms of having loved ones present when they went to the hospital for care. This affected those who were admitted to the hospital, too, as they could not have their loved ones around as needed for support:

> *"…People who are battling cancer during this COVID pandemic, for those who choose to bring a support system to the hospital when they are receiving treatment, could no longer do that. Because they limited how many people that can come to the hospital. …"*

Theme 8: Provider Commitment to Navigation Services

The provider respondents were asked whether they could see themselves still providing patient navigation services in five years; most of them responded in ways that indicated that they will likely not be in the field. There were those who anticipated progressing in their careers, *"Certainly, [I will] be in the oncology social work space, but not certain I'll be in the same role."* Another respondent also shared similar sentiments, *"For me, I'm definitely always inspired to advance in my career field…"* Two provider respondents said they would stay in the field of patient navigation and continue serving the cancer patients: *"I also started a nonprofit cancer connection resource center. One of the things that we do is provide navigation. So, to sum it up, yes, in one form or the other, I will be in a navigation role."* Another one also commented, *"If I could find another navigation travel position that would be ideal, um, even if I can you know, probably stay on at Washington Hospital Center, that would be ideal…"*

Key Informant Individual Interview Findings

We conducted seven individual interviews online (via Zoom) with cancer patients/survivors, caregivers, and a healthcare professional. In these conversations, we discussed patient navigation, experiences with (and without) patient navigation in cancer treatment, barriers to their utilization, and strategies to address barriers. The impact of COVID-19, related safety protocols, and other logistics on patient navigator utilization were also covered. The conversations were recorded with consent and transcribed, and researchers analyzed the transcripts for emergent themes. Through the constant comparative method, emergent themes were checked for inter-reviewer reliability. We found three emergent themes: 1) *understanding* *patient navigation*, 2) *experiences with patient navigation*, and 3) *how COVID-19 impacted the patient navigation field*, each with subthemes. The themes and subthemes echoed and complemented those found in the focus group transcripts.

Theme 1: Understanding Patient Navigation

Across participant groups, a variety of subthemes within understanding of patient navigation were discussed, including *defining patient navigation*, the *role and responsibilities* of the patient navigator, and the *perceived importance* of patient navigators to patients and within the cancer care team. For example, one patient/survivor participant said, *"It would mean that this person will be there to help you to go through with anything that you need, they will be like the person who [you] talked to instead of the doctor."* Another patient/survivor participant described the role of their patient navigator as, *"Mostly I've only had interactions with [navigator] as far as helping me connect with the transportation."* A healthcare professional participant described their appreciation for patient navigators*: "I mean I view it as like very important. I think it's kind of like a point of contact. I know that a lot of patients have a hard time reaching the doctors and the nurses or they're just too tired from chemo and they just have chemo brain and just can't like do a lot of these things."* Another healthcare provider describing how doctors perceive patient navigators expressed ambivalence, *"Some of the doctors are very appreciative of the fact that, you know, we make sure that they have on a meeting before the appointment. [Others] don't care for it, because it is time consuming."* In describing patient navigator calls before an appointment (as one example of how patient navigators' efforts are valued), a caregiver stated, *"It's been very helpful, yeah, because I think it took the fear out of the whole situation, you know."*

Theme 2: Experiences with Patient Navigators

Predictably, experiences with patient navigators varied and were both *positive* (helpful, friendly, empathetic/ compassionate, comfortable and informative conversations) and *negative* (unfriendly/unwelcoming, lack of empathy, lack of clarity of services). In addition, the topics of *expectations* (met and unmet), *referrals* (how patients connect with patient navigators, meeting outside of doctor appointments), *friends/family serving as unofficial patient navigators*, and whether *cultural and ethnic alignment* between patient and patient navigator is helpful were also detected in the individual interviews.

One caregiver described their patient navigation experience positively, *"It was a good experience, because I never knew there were so many agencies that you can receive help from. … It opened my eyes to a lot of information out there that we were not aware of and how to get … connected to that."* Meanwhile, a patient/survivor participant described a negative experience, *"No compassion or empathy, you know. It was really awful."*

A healthcare provider described a lack of clarity regarding roles and responsibilities between their work and that of patient navigators: *"There is kind of a like a merging, you know. There's, I think, a lot of crossover between what social workers are doing and the patient navigators. Since we are kind of serving in that role, you know, it just merges together and we do have actually a lot of crossover."*

Participants described patients being connected to patient navigators by doctors and nurses once a patient has been diagnosed with cancer. One patient/survivor said, *"You were at the doctor's office, you spoke to the nurse and she referred you."* Another patient/survivor shared, *"I'm the one that inquired about the patient navigation. They didn't ask the question and this is one that they refer to me to."* A healthcare provider stated, *"If you come to the cancer center, you* *automatically go through navigation, so you're assigned the navigator when you meet us at the door."* Another healthcare provider said, *"A lot of referrals are through the nurse and self-referrals. ... We including it in the welcome packet, but it just doesn't seem like a lot of people read it, or you know self-refer that way."*

In addition to (or in place of) patient navigators, patient/survivor participants talked about family and friends filling the role. One patient/survivor shared, *"My daughter, she looks out for me, makes sure I eat, even though I don't have an appetite for anything."* Another shared: *"I had a very close girlfriend of mine of over 60 years. Her cousin had gone through this experience. She was instrumental in helping me. You know, a few other women who had learned that I had cancer, they had [had] it and they shared some experiences and told me some things that I could do."*

When asked about the importance of patient navigators being from the same cultural or ethnic heritage as the patient/survivor, responses were mixed. One caregiver participant said, *"It would make a big difference about your culture, your racial profile. I feel that the health system is not equal to everyone."* A patient/survivor participant, on the other hand, said simply, *"I don't think that matters at all."*

Theme 3: Impact of COVID-19 on Patient Navigation

Healthcare providers discussed the impact of the recent pandemic and the consequences on patient navigation. One provider said, *"You know the transportation options are limited and a lot of them are like rideshare. So, you know, like you get picked up with them and there's like three other people that get picked up along the way and people are not comfortable with that."* Another said, *"a lot of them have lost their jobs."*

Burn-out, in part, due to navigators being allocated additional duties, is another important aspect of recent changes. One provider shared, *"It has stretched me tremendously and some days I'm feeling a little burned out."* Another provider said, *"If anything, it just became too emotionally draining for me. So, yeah, [I needed] a change in environment."*

Recommendations

Focus Group Recommendations

Participants in our focus groups shared many recommendations to improve and increase patient navigator services in DC. These recommendations are divided into five groups: *Best Practices*, *Increasing Service Awareness*, *Streamlining Navigator Services*, *Ideal Navigation Services*, and *Important Care Considerations*.

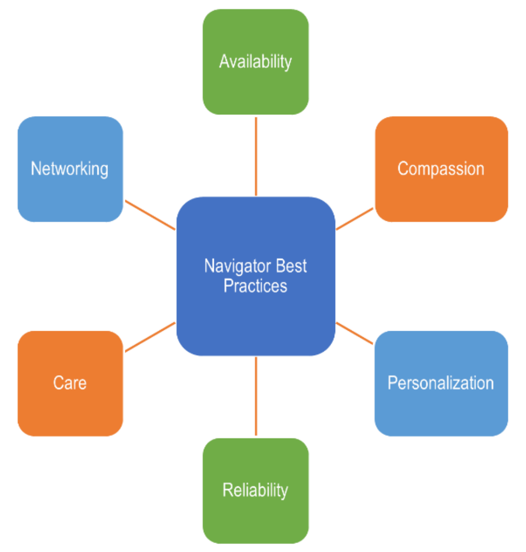

Figure 7: Best Practices

Navigator Best Practices

In order to be effective and deliver patient navigation services successfully, certain factors are key. These factors were shared by the participants. One of the key aspects of patient navigation is the *ability to show care*. The patient navigator should treat the patient in a manner that shows care and makes them feel loved. One of the providers said:

> *"I would say, even just you know what people might think of as like the little things, like if you see that a patient is coming in for their chemo you know, stopping and saying, 'hi' and just check in to see how they're doing and how their family is doing. People really seem to get a lot out of that…"*

Compassion is another essential trait when dealing with cancer patients, as shared by some of the provider respondents, *"…you know definitely compassion and being available works for me."* This contributes to successful delivery of navigation services to them.

Providers stressed the importance of being *available* to patients due to the pervasive nature of cancer treatment side-effects. The patient should be able to have access to them at any time they need assistance, *"…being accessible and available um returning calls in a timely manner. That does make a difference…"* A different provider respondent also shared, *"…just being available um being easy to access…"*

Reliability also came up as a factor that is key to offering successful patient navigation services. Patients should be able to rely on their navigators. One of the respondents commented about their experience with a patient they have been assisting:

> *"I've had scenarios with patients, let's say I've submitted a referral, in fact, I've done everything and then, when they call that department, they're like they've never received it and I've had patients come back and say. "[Name Redacted] I know your work, you, you always get back to me and when you say you're going to do something, you're going to do something. So, when they told me that, I knew that that was not correct, because I, you know, you've proven to me, you know what I'm saying that you are accessible, reliable, so that's key."*

Across participant groups, the importance of customizing and *personalizing* services and care provided was stressed:

> *"…the other thing that comes to mind, is just recognizing that it's not one size fits all, and so I really need to rely on my clinical experience and training to identify what is the best resource or the best solution for a particular patient in a particular circumstance in it, and I can't, you know, it's not a plug and chug model for me."*

Networking and expanding one's resources is very important as well, according to one of the provider respondents. Having connections and contacts who can be relied on when it comes to resource sharing is key, *"…just always expanding your community resources and networking."*

<u>*Increasing Service Awareness*</u>

Figure 8: Improving Awareness

The respondents shared a great many ways that awareness can be created concerning the availability of patient navigation services to the community. One way is through printable media, such as flyers and newsletters. Flyers can be distributed in the community to provide information on available navigation services, *"I heard flyers, door-to-door, if we could get some volunteers with some literature, to go door-to-door."*

Another suggestion was having resource persons in the community - people who are well known and trusted by community members. These individuals can be instrumental in helping to disseminate this information to the community: *"…every community has someone who's the person everybody goes to for information, how do we find those people and make sure that you know that this is another way that we can help people."*

Social media platforms such as Twitter, Facebook, and Instagram were suggested as ways to spread the information quickly throughout the community, *"Media communications, such as social media, Facebook, Twitter, Instagram, and that's on our personal pages, as well as organization pages, libraries, schools. You know, social media is one of the fastest and effective ways in getting the word out…"*

Faith-based organizations, such as churches, were also discussed. Pastors often share information with their congregation. Due to the personal relationship between pastors and their parishioners, they were seen as well-placed to share information concerning patient navigation services:

> *"…just getting the word into some of these pastors, because as soon as they, a parishioner says to the pastor, 'I have, you know, I've got diagnosed with cancer' or a family member has been, if they know hey do you know about these? There are people that can help and here's some ways to reach out to maybe the Smith Center or cancer support like whatever the organizations are, but just that w, you know, we really give like those."*

Another idea was working with the community leaders to share this information with the community, including organizations where the initiative is not related to cancer care or health. *"I just think tapping into these community leaders, whatever that leader looks like."* Community organizations were perceived as having an important role in the community.

Having doctors communicate the information to their patients in the hospital was also suggested as a way that information regarding patient navigation services could be disseminated. In addition, it was suggested that community meetings could be organized, where members gather and information is disseminated to them, *"Have meetings in the community about what's going on."*

Having information broken down by ward was suggested as a way of ensuring that accurate and helpful information reaches the members of the community. Sharing the types of assistance that are available in each ward was thought to be an effective way to make it easier on patients to track the resources they need, *"Have a form of directions broken down by wards in DC of patient navigator resources that can assist them with their needs."*

Streamlining Navigator Services

There were various suggestions shared by the respondents regarding how patient navigation services can be streamlined. There is value in having navigators with experience in the medical field, as shared by one of the providers: *"I primarily see value in having people with medical experience assisting with navigation. I've spoken with lay navigators who've shared their reflections that there's a very fine line of where they're able to help and where they're not able to help, and you know, certainly. Around any kind of medical information, they're not qualified to provide that…"* Medical knowledge might better equip navigators to answer complex questions from patients and guide them accordingly and accurately.

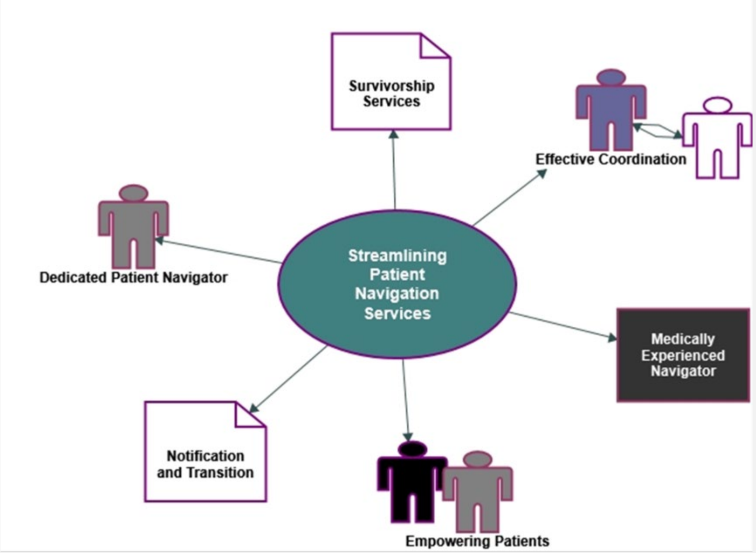

Figure 9: Streamlining Navigation Services

Participants shared that it would be great to have designated patient navigators for each patient and to avoid transferring patients from one provider to the next. This would ensure that the patient is well-guided and served:

> *"I do think that there are benefits to there being one dedicated person versus having to go through that handoff process and get to know another provider, so I think that would be better for patients, certainly wouldn't be more work for me, but sometimes, that's what you know best serves the patient."*

Having different people handling different resources might leave the patient confused about who to contact for which resources:

> *"…healthcare places, different systems have different roles and responsibilities for each person on the team. And so that makes it really hard for patients to know who do I call for this who do I call for that, who's going to help with transportation. Because oftentimes, each place they might be getting care or have experience with, it's different, and so I think that can create a challenge for patients."*

Having a smooth coordination between departments is very important in order to deliver efficient navigation services to patients. Communication should be effective, and clearances should be swift to enable the processes to run smoothly in favor of the patient. One of the provider respondents stated:

> *"…a huge challenge is to improve coordination among the service areas and she cited a major one, with our team, the central financial clearance department, who updates all the prior authorizations for treatment. If they had a clinical team in that department, that would help, because it's unfortunate causing a huge barrier and delays to patient care."*

The notification and transition process should be effective. When patients are transferred to inpatient departments, the navigators should be alerted so that they may provide help coordinating with the other relevant providers who are able to assist patients. One of the providers complained about current system challenges, *"…we're not always alerted when our patients go inpatient and there's a whole separate inpatient social work team. So sometimes it's kind of hard to figure out who to connect with who…"*

Cancer survivors should not be cut off from receiving navigation care services. There should be a system in place to ensure continuous care for them as they complete their follow-up visits. One of the providers stated, *"I think we could also build on services for patients in survivorship overall, because they do kind of get bumped off the priority list if they're not in treatment, if that makes sense."*

Patients need to be empowered to advocate for themselves, especially when they are not receiving the services they ought to receive, *"At the end of the day, I try and our team tries very much to empower patients to be their best advocate and to equip them so that they know how and when and where they need to access help."*

Ideal Navigation Services

There were various recommendations that were provided by the respondents about what they feel would be ideal when it comes to patient navigation services. There is a need for resource availability to ensure that the patients are receiving the care that they need, *"…be able to communicate with the patient to identify, um, just have a plethora of resources available, that you can provide to the patient…"* Caregivers should also be given some resources to help them navigate through the treatment and overall cancer journey of their loved one. Resources, in terms of expanding the patient navigator workforce, should also be a priority to ensure that each patient has a navigator who is not overwhelmed with cases. When there are more navigators, social workers will be able to assist in other areas, such as offering patients mental health services, *"…pretty much double the size of every department in a way, just to you know, at least from the social work aspect, to maybe free up the social workers to do a little bit more mental health care."* Another respondent also commented it would be better to have navigators attached to providers, *"…just having one patient, I mean, one navigator to the provider would make the world a lot better."*

There is also a need to make the systems a little easier to navigate, to ease the burden on patients: *"…for the system to be a little more easy to navigate, if that makes sense, um just like we say these patients are already dealing with a lot, so just maybe things like could be it takes one step to do this, instead of three. That would be ideal for me…"*

Accessibility needs to be improved to ensure that patients are able to access health care services in a timely manner. Scheduling processes should be improved to enable patients' access to providers: *"…there are access issues in* *terms of central scheduling and connecting with providers, and so I think trying to improve those things so that the health care system is, you know, more accessible to patients would be another idea."*

The manner in which care is provided has changed recently due to the pandemic. Therefore, it is important to enable patients to access care and resources virtually by empowering them to use technology: *"...just expanding services like, especially now with COVID, a lot of our patients don't know how to work like technology to do virtual things, so like providing that technology and maybe training to them. And just you know, getting them connected with as many resources as they need…"*

Important Care Considerations

When delivering care to cancer patients, there are a number of factors that should be taken into consideration. When sharing information with patients and caregivers, there is a need to use lay terms as opposed to medical jargon, *"...I think more so the information part, mm hmm, don't talk to us in doctor terms, break it down so that we can understand it a little bit more how serious the situation can be."* Patients and caregivers should be made aware of what to expect during the treatment process to help them better prepare. One of the caregiver respondents commented, *"...To be prepared like, they're not eating and they're losing weight, so let us know what to be prepared for and whether or not they're going to eat, you know."* Information should also be shared in the community about cancer and the resources that are available to promote better care.

Word Cloud 2: Clinical Care Considerations

Patient and caregiver participants overwhelmingly agreed that expressing empathy with cancer patients should be a key factor in providing care, and not just from the doctors, but from all of the staff. In general, individuals who provide care to patients should have a positive attitude, engage empathically, and not mistreat them:

> *"...just the empathy of doctors and not only the doctors, but the staff. You know work in the health field and a lot of people should not be there. They are there for a paycheck. And when they get to the point that they don't empathize with people or sympathize with what they're going through, they're pretty rough with them, you know. You go and get checked out in different areas and they're rough talking to you, they talking with a snappy attitude. They don't need to be there."*

Women who are diagnosed with cancer are generally vulnerable and are often terrified, especially those who have been newly diagnosed, so it is important to show empathy and handle them with care, *"I don't want to be treated as a person that you're doing me a favor or I'm some kind of charity case or whatever."* Doctors should express an understanding of patients' fears. A community service provider respondent provided an example of how doctors should speak to patients:

> *"I know, did you going through a lot, right now, but I have the Smith Center that can help you through this process and that you don't have to do this cancer by yourself, a lot of people think that they could do it, we have people that can help you along the way, be able to support you, through your process and just love on you."*

Providers, caregivers, and patient respondents all agreed that doctors who are providing care for cancer patients should be sensitive and very good listeners. One of the community service provider participants shared, *"…they need to be a great listener, who yes, some of these doctors don't listen."* Another patient participant stated that women of color don't feel heard by their doctors, "*I've heard so many testimonies of women who have gone through this process, and if it had not been for the love of the Lord, they wouldn't be here, because they weren't heard."*

Patience is another virtue that healthcare providers should exercise when interacting with their cancer patients, which is supported by some of the community service provider respondents, *"…first and foremost, I think they should, they need to be patient with a patient."* They should be able to reassure patients while sharing information on helpful resources. One of the community service provider respondents provided an example of an appropriate way that doctors can speak to patient in a reassuring manner, *"…it's good for the doctor to say, "Well, you know this program right here is good. I have other patients that are in this program. They really help you out they listen to you."* This type of provider/patient engagement can communicate care and provide comfort for patients, *"…the first oncologist that I had, I would say my referring oncologist, he was so gentle and just so kind and the temperament and the pacing of his voice was so comforting…"*

Mental health services should be made available to patients and caregivers as well. This can be achieved by sharing information about support groups and other mental health services such as therapy, *"…if you provide the information for them, they can go to the services."* Support group information should be shared with caregivers to help support their mental health challenges as well:

> *"Men and spouses are normally fixers, but cancer is something that they cannot fix, so sometimes we have to be able to allow them to express what it was like for them when their spouse came home and there were no breasts or there was this and that and the other, and I think sometimes the male counterparts, we leave them out. And so I think that there should be definitely a support group where they can as well get a chance to express how they feel because men are normally not talkers."*

Mental health services should be extended to the family of patients, including the children who may be going through mental stress because of their parent or loved one being sick with cancer. One of the patient respondents said it is necessary for every member of the family to be able to access mental health services, *"You know hearing mommy has cancer or and I gotta go to school and you want me to study, but I'm thinking about mommy. We got to make an outlet for everyone."*

Every patient should be given personalized care and providers should be mindful of offering patient what they need, *"…it's not a one size fits all, is it? You gotta help us get her according to her needs."*

There is also a need to do community outreach, which will ensure that those who are not able to go to the hospital can also receive education and information concerning cancer care and available resources. One of the patient respondents stated:

> *"…that quick response group that goes out there and continues to educate places we have buildings that are sitting that we got right around the corner from Martha's Table. I would love to have a community group that would come in. I would love to be one of the facilitators and help, because I'm definitely an advocate for what our communities are experiencing."*

The patient caseload per patient navigator is high, which often hinders the effective provision of care and resources for all patients in need. Therefore, there is a need to increase the human resource capacity to handle cases and ensure that impactful care is provided:

> *"…the rate of people getting diagnosed at the rate that we do. Will you all have the capacity, that you, how you handle the caseload, how many navigators will you be able to handle to make sure that -and I know we can't reach everybody, I get it. But how do you make sure that you have managed the expectations, so that you're impactful…"*

When patients contact providers, they should be able to access all the resources they require from one provider and not have to move from one source to another, *"…basically, it should be a one stop shop. I shouldn't have to go all over the place."*

Financial resources should be made available, since cancer treatment is expensive. Some patient participants supported this recommendation, *"…for those who don't have insurance, thanks be to God. I had insurance and I tell you, you just don't expect that one needle, one shot is $5,000. Where are you going to get it?"* There are financial baselines in place, which do not favor some tests, but are vital in ensuring that cancer is caught early in women. One patient respondent commented:

> *"One of the things that I am really advocating and rallying for now are the young women. A lot of the young women, you know, they're told that, at a certain age, you can only get a mammogram and then it's baseline. What about I mean, and then the doctor tells you, "…well you know we can't give them the 3D, because it costs too much." But you're saving a life…"*

It is therefore imperative to put some financial considerations in place, especially in terms of the insurance baselines to enable women access to the care they need to save their lives.

African American women should be offered proper treatment plans when it comes to cancer care and not sidelined and given inferior treatment recommendations, as compared to other women who are not of color. A comment made by a caregiver respondent:

> *"…if I was going to stress something, it would just be that the navigator should … look at the profile of the individual as just that. As an individualistic matter and to treat it as such, with as much empathy as possible, with much direct relevant information and make sure that the care and treatment is sufficient to remedy the cancer."*

Advocates are important to rally on behalf of the community and the people who have not been able to receive the care and resources that they need for their cancer journey. This is because not everyone is comfortable speaking up for themselves; therefore, having this level of support is beneficial:

> *"We really got to get advocates, people who are rallying for these individuals, especially when we talk about these different wards, we have to give people who really say, 'Listen, you may not be able to speak up, but I'll go fight for you.' I'm one of those people. I'm going to go fight for you, I'm going to find out where the resources are, where we get it, how do we get it, and how do we keep it in our community."*

Most of the caregivers complained about the overwhelming number of appointments that they have had to attend in a short period of time:

> *"…that was very frustrating, a lot of times for my sister, that she really wanted a lot of appointments right behind each other or close in the same, you know, timeframe. And it is true, all stretched all over the place. Sometimes, you go on Monday and then they're calling her right back for Wednesday, when she was trying to get the Wednesday."*

The appointments ought to be tailored according to patients' needs, which was supported by caregiver respondents. There are patients who do not drive and transportation can be a huge challenge for them, especially if they have frequent appointments to attend, *"I'm providing the transportation, she doesn't drive right now. So, you know gas prices are going through the roof, and going back and forth with the traffic in Washington, DC, it can be a challenge."* There are patients who struggle with attending multiple appointments because of the side effects of the treatment they are receiving for their conditions. Some of them tend to often be fatigued, which makes it more difficult for them to attend frequent appointments, *"I don't think the doctors really take into consideration when they come to these doctors' appointments, because they're tired. Not just the caregivers, but the patients are tired. And they're recovering from the last appointment…"* It is more advisable to have appointments lined up for one day to help alleviate the stress of having to go to the hospital several times in one week, *"I mean some things can be eliminated, we just get it done while you're there…"* One of the patient respondents also suggested the need for the patient navigators to accompany them to their doctor's visits, *"I guess the Navigator could have helped me, maybe go to my appointments or something…"*

When a patient is first diagnosed, there should be a database already in place with resources to make access easier. Information and resources should be sent to them immediately to help reduce patient stress levels:

> *"…as soon as a person is diagnosed, it seems like something should go to them right away, that says, you've been diagnosed, like hey, here's a support group or here's what you need to do, like something that's like quick, so you don't have like a lag you know. You get the bad news or, you know, quote-unquote bad news, and then you like, a few days, like you know going through your emotions and build it up…"*

This prompt sharing of resources will assist patients with starting their treatment process and likely prevent the unnecessary waiting period and worry regarding the unknown aspects of the process.

One of the caregiver respondents spoke about the need to have respite assistance for their loved one. This assistance was cited as a necessary for caregiver support, especially for those who have much to juggle and are also caring for other family members:

> *"I try to multitask and I'm not only taking care of my husband, I'm taking care of my grandchildren, I'm taking care of my sisters all the time. So, it would be nice if the Navigator or if they had something like they used to have*

> *candy stripers or somebody when I can't get to the hospital, somebody else could pitch in and be there, you know, and sit with the patient, so that they're not so all alone."*

Having transportation assistance available would be helpful for those patients who don't drive. Therefore, having resources available to help with transporting patients to and from the hospital will be beneficial , *"…neither one of us drives, so since we use public transportation, mostly transportation assistance would be very helpful…"*

Communication from the hospital should be directed to the caregiver, because they are the ones who are taking care of the patient. They should be involved in all communication, *"…they need to communicate and communicate to the caregiver, because we're the ones who's bringing them."*

Individual Interview Recommendations

First, the question of how to increase awareness of patient navigation services included, from a patient/survivor, *"TVs on the walls in the clinics and hospitals. I think they should put information on there about patient navigation."* Other patient/survivors suggested, *"doctors should be allowed to say, 'let me refer you to a person from the hospital that can assist you with different things;'"* and social media *"because everybody [is on] social media."* A health care provider suggested, *"In all the settings and everything, where we know the community is."*

Another area of improvement highlighted the need for more navigators, *"I think the problem right now is, you know, there's too many patients and too little people to really service them."* Healthcare providers talked about the need to take into consideration how time consuming the job can be, that they can see limited numbers of patients in a day and provide the services needed, *"Easily our conversations can go on for, you know, half an hour, an hour, you know. If they have emotional things."* Another suggestion from caregivers and patients included calling patients regularly to check on them: *"They should call, it should be like how you greet each other in the morning, the afternoon, or the evening. 'How are you doing? Are you doing ok?' … get the understanding [if it's] a good day, not a good day, and then they could say what [they] can do to help."* Another participant suggested, *"I think once a week is sufficient. Maybe twice, but definitely [at least] once a week, I think the patient navigators should check."*

Put together, the participants were in agreement that more patient navigation is important – more connection with the navigators, more navigators to decrease burnout, and more navigators so they can commit the time needed to support and connect patients and caregivers with resources.

Dissemination

Culturally Informed Dissemination Plan

Dissemination should neither be an afterthought nor focused upon only near the end of the research. In keeping with our CBPR approach, we prioritized dissemination and sought to build dissemination capacity throughout the planning and implementation of the research. This was accomplished through our Partner Network (PN) and network members. To this end, we were intentional about documenting all academic, scientific, professional, social, and community contacts and networks that we engaged. This allowed us to develop an inventory of contacts we used to identify and prioritize appropriate and diverse audiences for dissemination of study findings and potentially utilize for future study findings and collaboration activities. Our dissemination strategy will include several key audiences as outlined in Table 3, below. We will work with our PN and key stakeholders to develop and frame clear dissemination message points about patient navigation and the programmatic efforts that are accessible to community members and collaboratively present findings at academic, scientific, community, and lay health meetings, respectively. Third, we will develop a presentation to deliver to the PN, at a town hall meeting, other communities' venues, and special events, such as the National Black Family Cancer Awareness Week, Oncology Center of Excellence, U.S. Food & Drug Administration (FDA).

Table 3. Dissemination Plan

Audiences	Community Forums Lay Health Events	Media	Social Media	Community List Servs	Website Blogs	Peer-Reviewed Journals	Scientific Academic Presentations
Partnership Network	X	X	X	X	X	X	X
Community-at-Large	X	X	X	X	X		
Schools, Colleges Universities						X	
Academic/ Scientific Conferences		X	X		X	X	X
Legislative/ Policy Groups	X	X	X		X	X	X
Healthcare Providers*	X	X	X		X	X	X
Community-Based Organizations	X			X			
DC Grassroots and Advocacy Groups	X	X	X	X	X	X	X

* Healthcare providers include: physicians, nurses, CHWs, health para-professionals, patient navigators

Acknowledgements

We gratefully acknowledge our study participants living in the southwest (Ward 7) and southeast (Ward 8) quadrants of the District of Columbia for joining us and making this research endeavor a wonderful experience to share ideas regarding patient navigation and how we can help achieve health equity for all. Without you, our patient/survivors, caregivers, patient navigators, community service providers/advocates, and healthcare providers, this project would not have been successful. We would like to extend a special thank you to the Jane Bancroft Robinson Foundation for their generous financial support. We would also like to thank the Black Women Thriving East of the River Collaborative for their community advocacy, attention to detail and feedback in helping to ensure respect for participants and the community, transparency, and that all study aspects were culturally and health literacy appropriate. Finally, several individuals, academic institutions, community organizations, particularly from East of the River, and other stakeholders in the District of Columbia were key in this research, indicated as follows:

Black Women Thriving East of the River and the Jane Bancroft Robinson Foundation

- Erin Price, MSW, LICSW, OSW-C, Director of Young Adult & Psychosocial Support Programs, Smith Center for Healing and the Arts
- Aiyi'nah Ford, President, Strategy District PLLC
- Amari Pearson-Fields, PhD., MPH, Co-Chair, Patient Navigation Workgroup, Sokoya Consulting Group
- Kimberly Higginbotham, MPT, Patient Navigation Coordinator, Howard University Hospital
- Ronnette Moton, Program Associate, Institute for Public Health Innovation
- Kara Blankner, MPH, Director of Programs, Jane Bancroft Robinson Foundation
- Sade Anderson-Brown, PhD, Collaborative Member, Rodia LLC
- Manon P. Matchett, Grants and Operations Manager, Jane Bancroft Robinson Foundation
- Marsha Williamson

Cancer Support Community

- Rachel Ress, MSW, LICSW, CSC DC Community Navigator
- Eucharia Borden, MSW, LCSW, OSW-C, FAOSW, CSC Senior Director, Health Equity
- Elizabeth Franklin, PhD, MSW, CSC President Emeritus *(until January 2021)*
- Andrew Lewis, BS, MPH Candidate, 2022, former CSC Health Equity Intern *(July 2021 – December 2021)*
- Ted Miller, CSC SVP, former Development and External Affairs *(until January 2021)*
- Bridgette Trainor, CSC Manager, Development
- Eve White, MFA, CSC Director, Brand Management
- Nathalie Casthely, MBA, CSC Senior Director, Development @ External Affairs
- Karim Merchant, JD, CSC VP Development
- Sally Werner, RN, BSN, MSHA, CSC Chief Experience Officer
- Jeff Travers, MBA, CSC Chief Operating Officer
- Ken Scalet, CSC Interim CEO
- Debbie Weir, MSW, CSC CEO
- CSC DC Advisory Boards - https://www.cancersupportcommunity.org/csc-dc-advisory-boards
  - Leadership Advisory Board
  - Community Engagement Council
- Whitman-Walker Health
  - Amie Krautwurst, MSW, LICSW, WWH Senior Manager of Grants and Programs
  - Meghan Davies, MPH, CHES, CPH, WWH Chief Program Officer
- The Baskin Group
- For help with recruitment:
  - Washington Hospital Center
  - Alliance for Concerned Men
  - Breast Care for Washington
  - THEARC

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Appendices

Are you a Black female cancer patient or survivor who lives in Ward 7 or Ward 8, East of the River in DC?

IRB Approved at the
Study Level
Jan 10, 2022

We invite you to participate in either a virtual focus group study or individual interview about your experience.

Your Voice Is Powerful

FOCUS GROUPS ARE 1.5 HOURS
INDIVIDUAL INTERVIEWS ARE 1 HOUR

MONTH, DAY X, 2021, X PM, EST

The Cancer Support Community and Whitman-Walker Health, in collaboration with the Jane Bancroft Robinson Foundation and Black Women Thriving East of the River, are seeking cancer patients or survivors to participate in a study to learn more about cancer experiences in patient navigation.

This study has been approved by the WCG Institutional Review Board and is being sponsored by the Jane Bancroft Robinson Foundation.

CRITERIA

- Identify as a Black female cancer patient or survivor
- 18 years or older
- Read and understand English
- Be a resident of Washington DC living in Ward 7 or 8, East of the River

Interested in participating? Contact:
Rachel Ress, CSC DC Community Navigator
rress@cancersupportcommunity.org
(202) 552-4698

Stock photo. Posed by model(s).

CANCER SUPPORT COMMUNITY · HEALTH EQUITY IN ACTION · WHITMAN-WALKER HEALTH *we see you.*

Individuals selected to participate will receive payment for their time.

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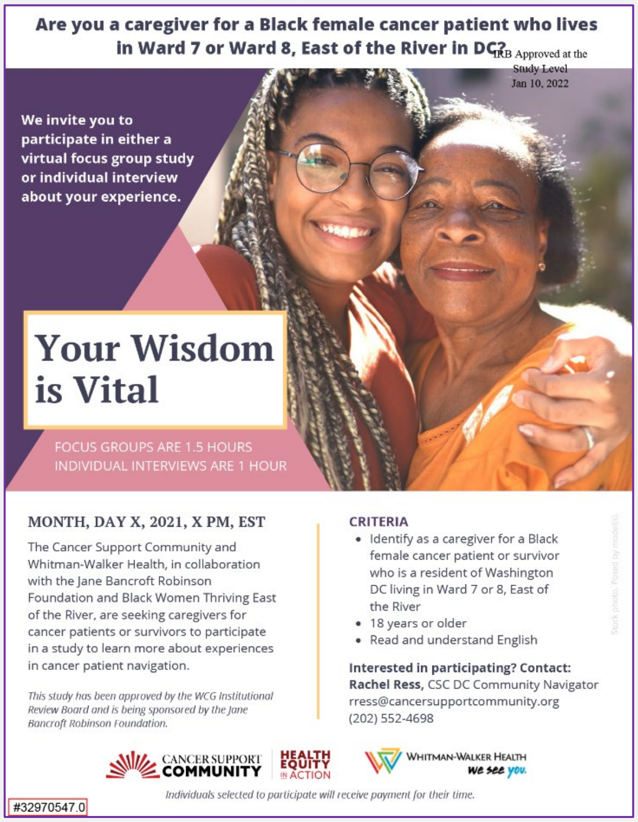

Are you a caregiver for a Black female cancer patient who lives in Ward 7 or Ward 8, East of the River in DC?

IRB Approved at the
Study Level
Jan 10, 2022

We invite you to participate in either a virtual focus group study or individual interview about your experience.

Your Wisdom is Vital

FOCUS GROUPS ARE 1.5 HOURS
INDIVIDUAL INTERVIEWS ARE 1 HOUR

MONTH, DAY X, 2021, X PM, EST

The Cancer Support Community and Whitman-Walker Health, in collaboration with the Jane Bancroft Robinson Foundation and Black Women Thriving East of the River, are seeking caregivers for cancer patients or survivors to participate in a study to learn more about experiences in cancer patient navigation.

This study has been approved by the WCG Institutional Review Board and is being sponsored by the Jane Bancroft Robinson Foundation.

CRITERIA

- Identify as a caregiver for a Black female cancer patient or survivor who is a resident of Washington DC living in Ward 7 or 8, East of the River
- 18 years or older
- Read and understand English

Interested in participating? Contact:
Rachel Ress, CSC DC Community Navigator
rress@cancersupportcommunity.org
(202) 552-4698

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Individuals selected to participate will receive payment for their time.

#32970547.0

Are you a healthcare professional in DC?

We invite you to participate in a virtual focus group study or individual interview about your experience.

IRB Approved at the
Study Level
Jan 10, 2022

Your Input is Needed

FOCUS GROUPS ARE 1.5 HOURS
INDIVIDUAL INTERVIEWS ARE 1 HOUR

MONTH, DAY X, 2021, X PM, EST

The Cancer Support Community and Whitman-Walker Health, in collaboration with the Jane Bancroft Robinson Foundation and Black Women Thriving East of the River, are seeking cancer healthcare professionals to participate in a study to learn more about the current state of patient navigation.

This study has been approved by the WCG Institutional Review Board and is being sponsored by the Jane Bancroft Robinson Foundation.

CRITERIA

- 18 years or older
- Read and understand English
- Be professionally employed as a cancer healthcare provider (such as a physician, nurse, social worker, patient navigator, financial navigator, nurse navigator, community health worker) in Washington, DC

Interested in participating? Contact:
Rachel Ress, CSC DC Community Navigator
rress@cancersupportcommunity.org
(202) 552-4698

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Individuals selected to participate will receive payment for their time.

Are you a community service provider to Black female cancer patients or survivors who live in Ward 7 or 8, East of the River in DC?

We invite you to participate in a virtual focus group study or individual interview about your experience.

IRB Approved at the
Study Level
Jan 10, 2022

Your Insight is Valued

FOCUS GROUPS ARE 1.5 HOURS
INDIVIDUAL INTERVIEWS ARE 1 HOUR

MONTH, DAY X, 2021, X PM, EST

The Cancer Support Community and Whitman-Walker Health, in collaboration with the Jane Bancroft Robinson Foundation and Black Women Thriving East of the River, are seeking community service providers to participate in a study to learn more about cancer patient or survivor experiences in patient navigation.

This study has been approved by the WCG Institutional Review Board and is being sponsored by the Jane Bancroft Robinson Foundation.

CRITERIA

- 18 years or older
- Read and understand English
- Be a community service provider to Black female cancer patients or survivors in Ward 7 or 8, East of the River in Washington, DC

Interested in participating? Contact:
Rachel Ress, CSC DC Community Navigator
rress@cancersupportcommunity.org
(202) 552-4698

Stock photo. Posed by model(s).

#32970546.0

CANCER SUPPORT COMMUNITY · HEALTH EQUITY IN ACTION · WHITMAN-WALKER HEALTH *we see you.*

Individuals selected to participate will receive payment for their time.