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Summer 7-27-2023

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## Early Stage or Curable Cancer Diagnoses in Minorities: A Journey of Survivors

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### **Abstract**

Patients diagnosed with early-staged or curable cancer experience physical, as well as, mental challenges associated with disease progression and treatment. Previous studies have demonstrated that minorities and underrepresented communities did not receive the same level of care in comparison to their non-minority counterparts. Previous studies have also demonstrated that health disparities among minorities affected their cancer journey. This study addressed: how medical disparities varied between minorities and non-minorities, the overall effects of the cancer diagnoses in minorities compared to non-minorities, whether these perspectives differed in male vs. female participants, and whether there were any possible communication barriers between cancer patients and their medical professionals. Participants also discussed the varied and unique experiences of being diagnosed with early-stage or curable cancers based on race/ethnicity, gender, age, and cancer diagnosis. Results indicated that minority and non-minority cancer patients had many similar health disparities and themes; however, minority participants had more health disparities and unique experiences. Male participants also received less support compared to their female counterparts. Lastly, there was a strong correlation between having an involved medical

staff team and having a greater cancer experience. Likewise, having a less involved and communicative medical staff team caused patients to have a displeasing cancer journey.

## **Background**

In 2022, there were over 1,918,030 new reported cancer diagnoses in the U.S (Siegel *et al.*, 2022). Cancer, notably characterized by the uncontrolled growth of cells, has claimed the lives of more than 10 million people yearly worldwide and in 2022, there were over 609,360 cancer deaths in the United States alone (Sung *et al.*, 2021; Cancer, 2022; Siegel *et al.*, 2022). Due to an increased mortality rate and the seriousness of this disease, patients have generated diverse responses to their significant cancer diagnosis. Cancer patients commonly reported feeling helpless and defeated upon hearing their diagnosis; yet, many physicians agreed that the patient's cancer journey is based upon their perceptions of treatment and involvement in meaningful activities that allow them to live well (Aubin *et al.*, 2010; Orri *et al.*, 2017). Due to significant technological advancements in the medical field, more frequent screenings have increased the chances of detecting various types of cancer in its early stages. Screening improvements have helped increase the cancer survival rate and inform others who may not be knowledgeable about the benefits of getting an early detection screening (Hendrick *et al.*, 2019; Siegel *et al.*, 2022). Unfortunately, there is no cancer cure; however, some cancers are considered “curable” in the sense medical advancements have provided better treatments and allowed a greater chance of survivability after their diagnosis. Though patients had different cancer diagnoses, it was vital that each of their journey’s was properly defined because the clinical documentation of their medical journey expedited the improvement in patient care and recovery (Rouse *et al.*, 2022).

Early-stage cancer is defined by discovering cancer early in its growth period, before it metastasizes and spreads to other body parts. Due to the diversity of cancer types, early-stage diagnosis varies within the cancer types. Cancer is typically detected early when the tumor is at Stage 0 or Stage 1 (Holland, 2018; Cancer: Symptoms, Stages, Types & What It Is, 2021). At Stage 0, cancer is identified before transmission occurs; at Stage 1, the cancer is still contained within one area of the body (Cancer: Symptoms, Stages, Types & What It Is, 2021; Langmaid, 2021; Markman, 2022). Once the tumor progresses to Stages 2-3, the tumor has grown and eventually spreads to nearby lymph nodes or neighboring tissues (Langmaid, 2021; Markman, 2022). As the cancer advances to Stage 4, it metastasizes via the cancer cells quickly traveling to other parts of the body through the lymphatic system or the bloodstream (Langmaid, 2021; Markman, 2022). When the cancer can be treated and properly controlled, the diagnosis is considered “curable” cancer. On the other hand, terminal (end-stage) cancer occurs once the cancer can no longer be managed because it has spread to a multitude of body parts or the tumor has gotten so large, treatments cannot suffice and the cancer is uncontrollable (Pérez-Herrero and Fernández-Medarde, 2015). Based on the severity and grade of the cancer, along with examining the patient’s medical history, the physician will recommend a personalized treatment plan to conclude the cancer progression.

Though various modes of treatment tend to be complex, there have been significant technological advancements in cancer treatments. Some of the more common forms of cancer treatment include: surgery, hormone therapy, chemotherapy, stem cell/bone marrow therapy, radiation therapy, targeted therapy, and immunotherapy (Pérez-Herrero and Fernández-Medarde, 2015; Debela *et al.*, 2021). In other cases, combination therapy combines multiple therapeutic agents in order to suppress cancer activity (Yap *et al.*, 2013; Bayat Mokhtari *et al.*, 2017). Improved

screenings and diagnostics ensured that cancer was detected earlier in comparison to the previous years (Loud and Murphy, 2017; Siegel *et al.*, 2022). Despite the near-universal incidence of cancer across ethnic and socioeconomic groups, previous studies have demonstrated that minorities, as well as individuals from underrepresented communities, do not receive the same level of care in comparison to their non-minority counterparts who also receive cancer treatments (Williams and Rucker, 2000; Gaskin *et al.*, 2009; Arnett *et al.*, 2016).

Members from underrepresented communities had unique health experiences and needs that were not addressed, as a result of: the lack of available resources, societal stigma, personal biases, and marginalized discrimination (Baptiste-Roberts *et al.*, 2017). Understanding, as well as, recognizing the causes in medical disparities may correct the disparity gap, help identify solutions, and improve their overall health. Racial/ethnic medical disparities, that were discovered within cancer treatment, arose from contributing factors such as: the status of the hospital, perceived personal image, socioeconomic status, insurance coverage, location, income, access to care, and other causes (Shavers and Brown, 2002; Williams, Priest, and Anderson, 2016). Compared to any other race, African-Americans had expansively higher cancer mortality rates and were more likely to not receive treatment (Williams and Rucker, 2000; Ward *et al.*, 2004; Murphy, Tseng, and Shah, 2010). This lack of treatment often originated from fewer healthcare sources within their geographic location, preconceived judgments about medical providers, stigmas, and possible perceptions of mistrust towards seeking medical attention. Previous racial injustices in U.S history, such as the Tuskegee experiments and the Henrietta Lacks immortal cell line generation, resonated with many minorities (Scharff *et al.*, 2010; Beskow, 2016; Budhwani and De, 2019). These incidents of mistrust have caused fear and a lack trust in the health care, which in turn reinforced negative stigmas towards receiving health care (Budhwani and De, 2019).

Receiving optimal care is fundamental to cancer patients because it can improve their overall quality of life and wellbeing. After their diagnosis, previous studies have shown some patients lacked a good support system and felt vulnerable or abandoned during their cancer journey; thus, affecting their mental health (Harrison *et al.*, 2012). Studies have also concluded that minority groups including African Americans, American Indian/Alaskan Natives, and Asian/Pacific Islanders had a diminished 5-year cancer survivability rate in comparison to their white/non-minority counterparts (Ward *et al.*, 2004). Likewise, since better palliative care for patients directly correlated to an increased survivability and quality of life, these results may parallel each group's treatment in society and lack of cultural support (Williams and Rucker, 2000; Temel *et al.*, 2010; Cole *et al.*, 2019). It was also noted that underrepresented minority groups received worse medical care in comparison to non-minorities, thus; directly correlating to their increased mortality rates (Schenck *et al.*, 2009; Temel *et al.*, 2010; Trinh *et al.*, 2012; Friedlander *et al.*, 2018; Cole *et al.*, 2019). Patients that received early and effective palliative care experienced a healthier outlook on their cancer journey and longer survival rates (Temel *et al.*, 2010; Cole *et al.*, 2019). In recent findings, patients also expressed how they needed additional information and support following their oncology surgery and discharge (Harrison *et al.*, 2012). Though these small acts of patient care may seem inconsequential, the treatment influenced how the patient adjusted to their diagnosis and their cancer journey outlook (Cegala *et al.*, 2008; Harrison *et al.*, 2012). Due to the fact a cancer diagnosis is a life-altering event, the quality-of-care delivery by health care professionals had long lasting physical and psychological effects on the cancer patient (Jefford *et al.*, 2008; Nipp *et al.*, 2016).

The patient's perspective on how cancer has affected their life had a significant effect on their mental health, but often, those perspectives are shaped by metaphors offered by society and other

medical professionals (Fernandez *et al.*, 2021). Cancer perspectives were socially determined and reflected the broader social context of the minority/majority experience. The way in which cancer perspectives were presented to patients by medical teams, is one way in which it was embodied (Fernandez *et al.*, 2021). There have been discrimination in how members of certain racial/ethnic groups have associated cancer metaphors, molding the outlook on their cancer diagnosis, compared to white cancer patients (Fernandez *et al.*, 2021). Metaphors specified to white patients, such as conceptualizing their experiences as a “journey”, stimulated a more optimistic and reflective outlook on their cancer diagnosis; whereas, experiences for patients of other races/ethnicities were cast as a “struggle”, “battle”, “war”, or “fight” against cancer by close influences and medical staff members (Fernandez *et al.*, 2021). These latter metaphors had negative connotations, which often reflected repressive inner thoughts, assumptions, or insinuations on how the cancer experience would be, and had more pessimistic mediating effects on their experience (Reisfield and Wilson, 2004; Fernandez *et al.*, 2021). Due to the negative metaphors given to non-minority patients by surrounding influences, such as: physicians, medical staff members, family, friends, and mass media outlets, patients often assimilated their cancer diagnosis into a fatalistic and adverse perspectives (Ramírez *et al.*, 2013). While these metaphors tried to associate an example to connect with a critical medical disease, the choice of linguistics may have inflicted more negative cognitive effects on patients ‘perspectives of their illness (Reisfield and Wilson, 2004; Harrington, 2012; Gustafsson *et al.*, 2020). Similarly, the language used in communication between the patient and the provider was presumed to impact patient perspectives and outcomes (Rocque, 2015). Those who received fewer positive forms of patient centered communication from their medical professionals often endured a weakened bond, lack of trust in their providers, and had less commitment to continuing their treatment (Rocque, 2015;

Street, Mazor, and Arora, 2016; Fernandez *et al.*, 2021). Despite having this disease, it was crucial for patients to be proactive about their diagnosis in order to identify suitable coping mechanisms and develop a healthier cancer experience (Kagawa-Singer, 1993; Umezawa, 2012; Nipp *et al.*, 2016).

Social inequalities in minority groups, such as differences in educational status, influenced how patients interacted with their medical professionals (Safran *et al.* 1997, Ward *et al.*, 2004; Murphy, Tseng, and Shah, 2010). Due to disconnects in the level of education and possible language barriers between medical professionals and patients, there was room for misinterpreting medical information. The difference in education status may have caused a sense of embarrassment, disrespect, or inferiority within the patient; therefore, they might not have felt confident in asking questions about their health (Katz *et al.*, 2007; Grissinger, 2017). On the contrary, medical officials may have lacked efficient communication skills; thus, causing the patient to further shy away from any medical concerns they may have had (Williams *et al.*, 2002; Wallace and Lennon, 2004; Aubin *et al.*, 2010; Grissinger, 2017). The fear of judgement was also a possible reason for minorities with socioeconomic disparities to avoid medical attention (Nonzee *et al.*, 2002; Katz *et al.*, 2007; Murphy, Tseng, and Shah, 2010; Cole *et al.*, 2019) and continue poor health practices (Rocque, 2015). Individuals may have also feared that a cancer diagnosis was a death sentence, the treatments were expensive, there were numerous difficulties, and the overall reaction from loved-ones after their cancer diagnosis. Often, loved ones react negatively after receiving the cancer diagnosis. Due to these fears, many felt it would be better to live without knowledge of this disease because it would become a burden (Nonzee *et al.*, 2002). To help combat these insecurities and stigmas, it is paramount for medical professionals to communicate openly and honestly with their



patient to become an ally and a source of emotional support/stability to overcome this disease (Rocque, 2015).

While cancer is prevalent across many demographic groups, this study seeks to understand early-stage curable cancer diagnoses in minority communities and how minority patient experiences differ from other non-minority populations. This study examined factors that contribute to the contrast in medical disparities between non-minority and minority patients, such as: environmental factors, socioeconomic status, healthcare coverage, structural/interpersonal forms of racism, education status, amount of toxin exposure, personal prejudices, genetic factors, and medical accessibility (Williams *et al.*, 2016; Zavala *et al.*, 2021; US. Department of Health and Human Services, 2022). Documentation of disparities and their potential causes, particularly within the cancer patients in the minority communities, allowed us to develop strategies to eliminate disparities and methods to improve cancer experiences. To emphasize the need for more minority-based studies to improve the future of their health and the healthcare system, this study serves a purpose to understand the effects of early-stage curable cancer diagnoses in minorities and underrepresented communities.

## **Methods:**

### Study Design

This study design utilized a modified grounded theories approach, which observes theories that are grounded in the midst of the qualitative data. The modified grounded theories approach suitably allows the flexibility for cancer experiences to illustrate richer theories involved within the data collection. All participants have experienced the phenomenon, being an early-stage or curable

cancer diagnosis, and this research helps identify patterns in perspectives and experiences across participants. The people's experiences are valid independent of the research. The production of this research assists in the establishment for voices that are often overlooked in research atmospheres. This design aims to reflect the real-world experiences via the theories and concepts found in the data. This research explores the complex and unique experiences of those diagnosed with early-stage or curable forms of cancer and set the framework for additional studies in the future.

### Recruitment

This study was conducted August 2022 through June 2023. This research combined newly collected data from minorities, as well as, existing data from 2016. The previous data derived from predominantly non-minority participants. Both groups of participants were recruited by networks of family/relatives, friends, and co-workers. The recruitment outreach expanded further based on these close networks. A research flyer was created to broaden the scope of collecting research participants for the newly collected data. The research flyer included a QR code, linked to a Google forms survey, to properly select eligible participants. The participation pool expanded by sharing the research flyer via text messaging and social media platforms such as: Facebook, Snapchat, Instagram, and TikTok. The flyer was also advertised around local college university settings and offices. To promote and expand the research, a reference video was uploaded to TikTok. TikTok viewers were encouraged to like, stitch, comment, and share the video for more interaction.

### Participants

Participant eligibility was based on an individual's ethnic, racial, and sexual minority status (such as men), as well as an early-staged or "curable" cancer diagnosis. Individuals in remission were also eligible to participate. Individuals completed physical or electronic consent forms to indicate their willingness to participate in this study. If the participant was under the age of 18, a parent or guardian consent was required. The entire sample consisted of 46 individuals, mostly from racially and ethnically diverse backgrounds (refer to Table 1 for the Demographic Information). Eligible and willing participants then scheduled a face-to-face or virtual interview.

Virtual interviews were conducted via Google Meet and a personalized link was sent to their email. In-person interviews were conducted at mutually agreed locations such as: local coffee shops, private residencies, local restaurants, public libraries and bookstores, etc. Interviewing discussions followed a questionnaire, about their cancer journey (refer to Appendix for the Interviewing Questionnaire). All participants interviews were audio recorded and their identity remained/(s) anonymous for the protection of their privacy in order to de-identify the data. After the interviewing process was finished, audio recordings were uploaded to a computer and analyzed using the Microsoft TEAMS transcription/recording software and other transcription software from Rev.com. After the analysis was conducted, the participant data was generated into Microsoft Excel to compare and contrast thematic concepts, as well as, overarching themes.

### Ethics Approvals

For this study, an IRB approval (IRB-FY22-521) was authorized preceding the initiation of interview collections. Participation was voluntary and participants had the prerogative to withdraw

consent at any time, under any circumstances. All personal data collected was confidential and no personal information was disseminated. All consent was obtained before initiating the interview. After consenting to the interview, with an estimated duration of between 60-120 minutes, participants provided their cancer journey and diagnosis. To ensure the safety and confidentiality of the participants, each participant recording was given a randomized code. After the interviewing portion was complete, all interviews were anonymously stored and reviewed.

### Data Collection and Analysis

All interviews were audio recorded to capture the verbiage, vocal patterns, intonations, fluctuations, emotional responses, and overarching response pattern. Verbal recordings were then transcribed into written transcript. A modified grounded theories approach was utilized to approach the analysis of this participant sample, to examine the unique experiences of those diagnosed with an early-staged or curable cancer diagnosis (Alnsour, 2022). Transcripts were read and analyzed to entirely comprehend the essence of the participant's cancer journey. Interviews were also analyzed to see any structural or behavioral similarities and differences. Any key words, codes, or patterns noticed within the interview transcript, while also comparing and contrasting any overarching behavioral themes, were documented (Alnsour, 2022). Certain key words were assigned a code and particular codes were grouped to form connections amongst themselves. These connections tied together codes to form categories. Lastly, categories are utilized to detect pivotal themes within the research data.

### Thematic Saturation

During this study, thematic saturation was reached among the subset of African American/Black female participants after 5 interviews. It was noted that the same themes were occurring within the interviews and there was no new thematic information discovered. When this occurred, this study switched to encompass the modified grounded theories approach. This modification was used to mitigate the relatively small sample size.

### Results:

The sample subset has a total of 46 participants, including interviews of 27 minority and 19 non-minority participants (from the pre-existing data set), diagnosed with an early-staged or curable form of cancer. Individuals in remission were also included in the participation pool. From the sample, 5 minority and 3 non-minority participants had undergone multiple occurrences of the cancer returning.

Table 1: Demographic Information from Non-Minority and Minority Participant Interviews

<b>Total Sample (N=46)</b>				
<b>Characteristic:</b>	Non-Minority Participants (N=19)		Minority Participants (N=27)	
<b>Age (years)</b>	<b>Mean</b>	<b>Range</b>	<b>Mean</b>	<b>Range</b>
Age at Diagnosis	52	32-63	50.5	19-86
Age at Interview	58	47-67	60.5	25-89
<b>Gender</b>				
Female	19		17	

Male	0	10
<b>Race/Ethnicity</b>		
Caucasian	19	5
African American/Black	0	20
Hispanic/Latino(a)	0	2
<b>Marital Status</b>		
Single	3	5
Married	15	17
Divorced	1	2
Widowed	0	3
<b>Estimated Income</b> <span style="float: right;">*Reports from willing participants</span>		
Less than \$25,000	-	2
\$26,000-\$50,000	-	4
\$51,000-\$75,000	-	3
\$76,000- \$100,000	-	2
Over \$100,00+	-	6
<b>Employment Status</b>		
Employed	18	18
Unemployed	1	1
Retired	0	6
Disabled	0	2
<b>Education</b>		

Unknown	3	0
Some College	2	3
College Degree (Associate's, Bachelor's or Master's)	11	21
Graduate Degree (PhD or Doctoral)	3	3
<b>Diagnosis</b>	<b>*includes reoccurrence of additional cancer form</b>	
Basal Cell Carcinoma	1	0
Breast (including Ductal Carcinoma in Situ (DCIS))	8	9
Cervical	3	1
Colon/Colorectal	*3	2
Hodgkin's Lymphoma	0	1
Kidney	0	1
Lung	1	*2
Malignant Melanoma	1	0
Multiple Myeloma	0	2
Non- Hodgkin's Lymphoma (Large B-Cell Lymphoma)	0	1
Ovarian	0	1
Pancreatic	0	1

Prostate	0	6
Testicular	0	1
Thyroid	1	0
Uterine	1	0

Table 1 indicates demographic information from both the non-minority and minority participants. The minority participant subgroup had a notably wider age range, for both the age at diagnosis (19-86 yrs.) and the age at the interview (25-89 yrs.) in comparison to the no-minority group. Both groups had similar reports of marital statuses, employment statuses, and education levels. No income data was reported from the non-minority participants because their data came from pre-existing interview. Using the census tract to estimate the income based on zip code, minority participants had an overall average estimated income of \$60,677; whereas, non-minority participants had an overall average estimated income of \$84,071. Lastly, minority participants had a noticeable wide range of diversity regarding the type of cancer diagnosis.

Throughout the interviews, both from the original subset of interviews and the newly conducted interviews, there were prevalent themes among both groups (i.e., non-minority and minority participants). Upon the initial response to their cancer diagnosis, participants had a mixed variety of emotions. There have also been noticeable barriers to seeking medical care. In the midst of this sudden life change, many participants had a variety of sources for information. Even though cancer is not a disease where all of the effects are uniform, the effects of cancer were certainly comparable. From this experience, participants explained diverse and comparable perspectives on their outlook on life after their cancer diagnosis. Participants also reported how an important support system was crucial for their wellbeing. While these themes are very prominent throughout the interviews, new additional themes were also discovered. Additional themes acknowledged: technological advancements, ageism, stigmas, communication in relation to medical staff members, and



physical/emotional impacts. There is also the discussion of unique experiences, primarily within the subset of minority participants.

### *Importance of a Support System*

Nearly all participants identified close friends and family members as important components of their support system. Some participants openly told family members and friends when they were initially diagnosed:

“[Husband] He was a little bit at a loss. Felt confident in me. I think he was very confident that what I was doing was solid. I had support from that ... He wasn't second guessing me, or nothing like that. It was very "you know what you're doing. I'm here. I don't really know what to do to add value, but I'm here." Which is kind of all you could ask, because I wasn't asking him to do anything beyond be there. I think I cried some, just because you get all, a lot of emotion”

- Caucasian, Female, 58, Breast and Colon Cancers

“My family and groups.... people that I trusted because I was really in the first few years.

It was all about what I could do”

- African American, Female, 63, Multiple Myeloma

whereas, others wanted to keep their diagnosis more covert to avoid feelings of embarrassment, shame, pity, or chaos among their loved ones:

“Interviewer: Do you think the doctors and the people that care for you know that you're sad?”

Interviewee: I don't tell them that I'm sad. After they take my blood and they come back and tell me what level it's at, I smile. I'm like, "Okay." Once I get the news that I'm okay. Everything is normal. They used to work normal. Everything is normal”

- African American, Female, 63, Chronic Lymphocytic Leukemia

Co-workers and neighbors within their close network were another great form of support and sources of information:

“I sought out survivors within my own network.... He [the friend] was the husband of one of my high school guy friends who had stage 4 breast cancer. I talked with [him] about it”

- Caucasian, Female, 58, Breast and Colon Cancers

Additionally, few participants expressed obtaining support animals to help comfort them through their cancer journey. It is also noted that medical providers and staff were included as great systems of support. There was a direct correlation between the involvement of the medical staff member

and their patients' overall perspective regarding their cancer journey. At times, the bonds were so close they were seen like family:

“My second urologist...That physician is now like family to me... His motto is, I'm going to treat you like family, so that was very important to me”

- African American, Male, 55, Prostate Cancer

### *Barriers to Seeking Medical Attention*

While the healthcare industry is still evolving, there are still many impediments to obtaining proper medical attention. One of the most common barriers to health was an overall lack of knowledge, regarding their cancer diagnosis. Various participants did not initially receive care because they were unaware about the available cancer resources to help support them monetarily, mentally, physically, and emotionally. As a part of these resources, other participants have mentioned the lack of medical insurance due to expensive prices. As a result, they could not afford the treatments and delayed their care. The lack of knowledge was heavily affiliated with the second most common barrier to seeking attention, the lack of insurance:

“I wish I had insurance to help fund my doctor’s visits when I was originally diagnosed. There was a delay in my care because I thought I had to have insurance to go see the doctor...At the time I didn’t have any insurance so I thought I couldn’t go to the doctor. I kept feeling that lump and decided I was going...I didn’t know they had grants out there for your healthcare and they gave me a grant and no one tells you these things”

- African American, Female, 65, Breast Cancer

Another patient was forced to keep “checking with the lab that” she knew her “insurance used” to monitor her coverage because the magnitude of good quality insurance dictates the level of care and number of services accessible to the individual. Without health insurance, medical costs were more expensive. Contrastingly, there were individuals who had had insurance, yet still did not go to the hospital due to negligence and an ultimate lack of knowledge about cancer health services:

“Matter of fact, the only thing that I know that you couldn't get a lot of people, even with the insurance, they really wasn't going to the doctor's no way. A lot of people have access to it, and they still don't go... Unless there's a real, real problem, that's when they'll go”

- African American, Male, 78, Prostate Cancer

Many participants spoke of navigating their busy work schedule with their treatments and the financial burden this cancer diagnosis has cost them:

“[The] recession hit we're paying for my mom to go to the doctor and insurance does help but it doesn't cover everything so we're paying for that, and then um, my dad lost his job because he was taking off... we probably would have been fine if we weren't paying so much money into her healthcare, so I don't really understand why it costs so much and I guess over the span of time that she's been sick the amount of time that has gone into that is enough to like put a kid through college”

- African American, Female, deceased at 43, Breast and Lung Cancers

Another patient expressed how:

“If they [parents] weren't supporting me financially, I wouldn't have been able to afford anywhere near the kind of treatment I was able to receive. It might have been a lot harder. I might have not had even been able to afford treatment. I mean, this was an incredibly expensive diagnosis. I mean, we spent well over \$200,000 on all my hospitalizations, and that was with decent insurance”

- Caucasian, Female, 25, Hodgkin's Lymphoma

Finances for the coverage of the expensive cancer treatments were often influenced by the personal income of the cancer patient, and how much their insurance (if applicable) could cover. The census tract (based on zip code) displayed an average estimated income of \$60,677 for minority participants and \$84,071 for non-minority participants. Very often, participants expressed how they had to schedule their treatments around their work schedule because they “can't not afford to miss work”. Some participants also expressed how "it's almost like a gamble" deciding whether they attend their treatment or go to work. Others have reported receiving their treatments on their lunch break:

“I did my chemo treatments once a week on Wednesdays. Was pretty much there for six to eight hours. And I did my radiation treatment every day on my lunch break... [I] explained that I would need an extra lunch break, you know, to kind of have lunch and do my treatment”

- Caucasian, Female, 47, Cervical Cancer

Many participants delayed seeking medical attention due to pre-existing prejudices and bias from previous experiences with medical staff members. Due to those instances, there was much apprehension in seeking medical care. One participant openly addressed how and how his medical doctor did not care about his health:

“I'm not going to lie. I mean, seriously. For you to be able to see somebody die, he said I refused treatment, and like I said didn't even know I had it [heart condition and cancer]. That's your bias. Some people are like that. They ain't going to do what they need to do to keep us, save us. [They say] Why waste my time trying to save you?”

- African American, Male, 62, Lung Cancer

Particularly among more minority participants, communications and language barrier between medical staff providers and patients caused much reluctance in seeking care. For non-English speaking patients, there were language barriers and preconceived judgments that caused them to avoid seeking medical attention due to bad treatment:

“It's like it's an authority thing. There've been times where it's a race thing too. I grew up in California in Los Angeles, so it's a very diverse, very mixed area. But I remember a couple of times too, being at the doctor's office or if I'm there to help translate for my parents, and it's not like... You know my parents understand English and they could speak English, but just some words don't translate.... I was just there to translate those specific words but if there was a word that I didn't understand or they understand, the doctors just scoffed at it... we're asking questions, we don't know. So we're here to ask you so you can

tell us, but don't think any less of us or don't think that we're incapable of understanding what's going on”

- Hispanic, Male, 43, Prostate Cancer

Actions from medical providers, such as the previous example, further the rift between minority communities and their willingness to trust the medical community with their health.

Aside from language barriers, access to care was another barrier to medical attention. Some participants lived in a medical desert or in areas where the healthcare was lacking in substance. One participant expressed how her mother forced her to relocate back to her hometown of Marietta, in order to receive care at Wellstar Kennestone Hospital because her previous medical team was causing her health to fail. They denied her health was risk:

“So I kept going back to the doctor about that [swollen lymph nodes]. I would mention to them every time I'd come in, "Hey, so my lymph nodes," and they're like, "No, you're sick. That's why your lymph nodes are swollen.". So it just escalated from that. Then I had a bunch of people telling me they thought I had mono. They did test for mono. It wasn't mono.... So I went to the ER and that's when they finally did something about it, after I had to ask them repeatedly. They told me, "Well, you're just thinking about it too much. You're not going to have cancer.". It was really annoying, being told that there's no way I have cancer when I in fact did”

- Caucasian, Female, 25, Hodgkin's Lymphoma

### *Initial Response to Cancer Diagnosis*

Upon the initial diagnosis, nearly all participants expressed signs of shock and fear, believing a cancer diagnosis was an automatic “death sentence”:

“When I was told I had cancer, immediately I thought: I’m [going to] die. C-A-N-C-E-R. When you’re told that, I thought there was no help. “You are going to die. You got it now. You are going to die.”. That’s what I thought.”

- African American, Female, 59, Breast Cancer

Another participant stated:

“I was just thinking I wasn’t going to be here for my grandkids. It was just all kinds of things going through my mind but, that’s what I was worried about. Death, the whole time. I was worried about death and what was going to happen and I was just scared and I couldn’t sleep.”

- African American, Female, 53, Breast Cancer

While many openly accepted their cancer diagnosis, others were in a constant state of denial and completely rejected the state of their health:

“She had really good doctors, I think just for her she was kind of in denial...she’ll kind of just be like well, I’m a woman of God and you know, kinda push away what they’re saying.



She was also trying to keep us from knowing things. But I would figure things out like the older I got, and I would read things on my own. Nobody else would know, so I'd kind of known for a while and I would kind of keep it to myself”

- African American, Female, deceased at 43, Breast and Lung Cancers

Coupled with denial were often signs of frustration and anger because their health was declining. Many participants who displayed anger or frustration were also perplex about how they developed cancer because they were under the assumption they were in perfect health; there were no symptoms of cancer. On the contrary, a relapse of the diagnosis occurred within eight participants. Due to pre-existing family medical issues and health experiences, many participants also witnessed emotional relapses from past memories:

“My first biopsy was traumatizing and I brought that fear into my second and third biopsy. I shared that experience and they [the staff] were very mindful...My pain was significantly lower because they were willing to give me whatever I needed”

- African American, Female, 62, Breast Cancer

Some had previously battled mental health issues and their diagnosis caused them to relapse into their prior mental state; however, nearly all participants developed a determination to fight for their life:

“[Cancer is] something to fight. It's something to fight, something to be aware of, something to keep control over. Keeping control over it by nip it in the bud, so I'm all about nipping it in the bud”

- African American, Female, 73, Breast Cancer (DCIS)

### *Outlook on Life After Cancer*

Though many participants demonstrated much uncertainty and ambiguity among their cancer diagnosis, almost all participants were hopeful for the future:

“This [cancer] doesn't have a criteria for any age or color but, know that you're not alone, that there are opportunities to move forward to if that's what you want”

- African American, Female, 73, Breast Cancer (DCIS)

After their cancer diagnosis, some participants were hopeful for the future, yet, reflected on past life decisions. Participants extensively explained their regretful past decisions in life; however, their cancer journey has developed a new appreciation for life and created feelings of peace with those past decisions:

“Well, so before my cancer diagnosis, I had gone through a lot of mental health struggle. So I had a suicide attempt in 2018 that landed me in the ICU.... So I struggled a lot with that, and by the time I was starting to feel better, that's when I got my cancer diagnosis and it brought everything back. When I found out that I could die from this, it made me feel stupid for wanting to kill myself, because I was like, "Oh, now that it's going to be taken

away and it's not my choice... cancer was making my life a little better, because it started to make me appreciate a lot of things”

- Caucasian, Female, 25, Hodgkin’s Lymphoma

Few expressed how they previously took their life for granted; however, their perspectives have changed due to the realization their life could be gone:

“People ask me why...I’m full of energy and life and love...I say because I almost died. So I do not take every day for granted. I live life to the fullest...every day. Because you just never know, you know, what’s going to happen to you”

- African American, Female, 59, Breast Cancer

Though there was much ambiguity that surrounded life after their cancer diagnosis, a plethora of participants expressed their strong fast reliance on faith and religion to help them on their cancer journey:

“And I just put everything in the hands of the Lord.... I trusted the Lord to see me through it and he said he'd never forsake me. He's been with me every step of the way and he gave me doctors and nurses that were loving and caring”

- African American, Female, 89, Multiple Myeloma

Another patient, who often preaches their faith, declares that:

“I had a peace about everything. I got up one morning and in [the book of] John, there was a scripture that I prayed and the Lord said, "Where you prune something so it'll bring forth more fruit." That scripture spoke to me and it's like the Lord said, "I'm pruning you to bring forth more fruit. I'm going to use this for my glory... The nurse came running in on Wednesday night about nine o'clock.... He [the doctor] said, "Tell your family and friends and church and there's a miracle. Not one tiny bit of cancer was in your lymph nodes and your appendix and your colon. It stayed there in that one spot and we got everything." He said, "You're not going to die of cancer, I guarantee you that. We got everything.".... He said my liver was clean as a baby's liver.... He said, "Where those spots went, I don't know...God touched you."”

- Caucasian, Male, 65, Colon Cancer

There were also participants emphasizing how they "did everything right and still got cancer":

“I was in shock. Like, you're kidding me. Because I exercise, I eat right. I'm a health educator. I'm on top of my health. How could this possibly be happening to me?... It just felt like I couldn't believe it”

- African American, Female, 49, Breast Cancer

Therefore, they continued to maintain their health because this disease could always reoccur but with the proper care, it could be well managed:

“I’m more proactive about particularly sugars.... So my husband and I have always been active in our lifestyle, so that hasn't changed. I'm just more apt to keep up the physical activity.... And so I exercise, I try to eat right. I watch my portion control. I actually triage myself every morning with weight, blood pressure, heart rate, all of those different things just to see, and I track it to make sure that there's not any changes. And so that I know myself when things are off, what's going on that may have caused those numbers to go off. So I keep an ongoing log of what my basics are”

- African American, Female, 49, Breast Cancer

### *Effects of Cancer*

Although there were many physical, as well as emotional, effects cancer has positioned upon its inhabitants, anxiety and depression were the two most common emotional affects. Respectably, some participants expressed a positive experience and painless treatment:

“I’ve had the best of care, the best of love. They're about the most loving, caring people I ever met. It shows. It shows, just like I said, from the time I get in that van to the time I get over to the hospital and leave the hospital and they bring me back home. The doctor ‘s love shows from their actions and the way they talk to you”

- African American, Female, 89, multiple Myeloma

In contrast, participants detailed the more intensely emotional and physical effects from enduring their treatments:

“They scheduled me for an MRI and I fell off the table. Two doctors caught me and the pain was increasing and they caught me before my face hit the pavement...those doctors heard me scream because I couldn't support myself”

- African American, Female, 63, Multiple Myeloma

“My self-esteem was really, really poorly affected. I remember I'd look in the mirror and [not know] what I was looking at...[I'd] refuse to look in the mirror. It affected my social life. I wasn't able to talk with my friends”

- Caucasian, Female, 25, Hodgkin's Lymphoma

A wide selection of participants initially were not concerned about cancer prior to their diagnosis; however, there was increased empathy for those who have gone or are currently fighting cancer after their diagnosis:

“I felt sorry for the people that had it. And I was always wondering why they hadn't found a cure for it. And then children were coming down with it and babies. You know I was real sad, little innocent little babies and children and they never done anything. You know what I'm saying? And to be- I'm stricken with that...it's just terrible. And that's what I felt about cancer. Just hoping I didn't get it, or my children didn't get it, or grandchildren, you know?”

- African American, Female, 59, Breast Cancer

There were also reports of increased levels of productivity due to their health being in such a frail state. Something that was once taken for granted, suddenly had the opportunity to be completely taken away.

After withstanding the battle of cancer, almost all participants developed a sense of self-advocacy to continue fighting for their health care needs and matters. They gained the sense that their health is a major priority and were willing to speak up about their medical needs.

### *Source of Information*

From this study, the most participants gained their sources of cancer information, by researching on the internet and utilizing social media. A second most common form of information included vicarious experiences from close friends, family, and coworkers who had previously been diagnosed with cancer:

“Interviewer: I know you were really proactive in getting information. Where'd you go for information?”

Interviewee: Friends.... people who had been through it, other survivors, and the internet. I actually got into some pretty deep websites reading studies and things; some of the traditional: the Mayo, and WebMD, and the Cancer Society”

- Caucasian, Female, 58, Breast and Colon Cancers

Participants were able to connect and locate others cancer patients with comparable diagnosis, as well as, finding alternative support groups in their area:

“I think it was more comforting to find that much information, and also...people leaving behind their thoughts and stuff because they’ve gone/[going] through it.”

- Caucasian, Female, 25, Hodgkin’s Lymphoma

From the support and social media groups, participants were able to learn more about cancer from other participants, via vicarious experiences. Many participants sought information from close family members/relatives, co-workers, and friends who had undergone the battle with cancer.

Lastly, medical staff members were also highly knowledgeable sources of information:

“I see my doctors for information. See, I've been going to the doctors where I've gone for years. Dr. Agwa is an outstanding doctor. They're young doctors, and they're caring doctors”

- African American, Female, 89, Multiple Myeloma

A direct correlation between the level of engagement from the medical staff member to the patient and the agreeableness in their treatment was very distinguishable. Depending on the level of involvement and care from their medical providers was very influential in which information was accepted or rejected from the cancer patient.



### Technology Advancements and Their Diagnosis

Some participants have addressed their noticeably suspicious screening results; however, some of their medical professionals failed to properly address this serious matter. Other patients have expressed how without these technological advancements aided in their survivability. These advancements were able to successfully help detect their cancer earlier; therefore, they are able to move forward in life with the proper cancer diagnosis and treatment. Contrastingly, participants have voiced faults in technology detecting their screening abnormalities. There have been reports of being misdiagnosed due to the fault in the training and monitoring of technicians, as well as other medical staff, in order to properly detect these abnormalities.

### Ageism

Participants that were diagnosed with cancer earlier in life encountered forms of ageism with their cancer care. Though younger patients received more sympathy because they were diagnosed at an earlier age than the average cancer patient, many patients report being gaslighted into believing they did not even have cancer:

“I remember feeling quite unbelieving of it. It was something that I had been told repeatedly wasn't real, and to be told just bluntly that I had it was very upsetting.... There was an older lady nurse who was asking me about my symptoms in the ER. I told her, "I know this is a lot, but I looked up my symptoms and I believe it might be Hodgkin's. If you guys can find some way to help get diagnosis for that or try to find a... just consider it." Right? She laughed at me. She said, "Honey, you're young. There's no way you have cancer.... She

treated me like I was crazy. It was so invalidating. As medical professionals, you need to listen to your patients”

- Caucasian, Female, 25, Hodgkin’s Lymphoma

A few older participants expressed how medical staff lack empathy for them, due to their declining age and assumed lack in quality of life:

“But it's like I kind of felt like they were trying to save one race, you know what I'm saying? And not save everybody. So you know, I kind of felt like that. Or to say you elderly, because I don't think they want to take time with the elderly...They’re old, so this is probably the end of line for them”

- African American, Female, 59, Breast Cancer

An additional participant concludes how a former physician underestimated her intellect due to her age, as well as skin color:

“Particularly about my age that I should not have known anything, but to accept anything that he said. But he didn't know all the time when I left there, I wrote down notes. I think age, I think, had an effect of his negative attitude. My color had an effect on his attitude. He didn't think I had the knowledge that I should have had at my age. But I know my other doctors say I'm very smart and very knowledgeable for my age. I have a good mind, and I don't think he expected that of me. I think he probably thought I was a stupid, black woman”

- African American, Female, 89, Multiple Myeloma

### Stigma

One of the most common stigmas surrounding cancer was the notion that cancer is a disease for old people; however, cancer does not discriminate. The youngest participant was diagnosed with cancer at 19 yrs. of age. The minority subgroups had a median age at diagnosis of 50 yrs.; whereas, the non-minority group had a median age of 52 yrs. Unfortunately due to external factors, genetics, and lifestyle choices, it is a luck of the draw regarding who becomes diagnosed with cancer.

Many participants from the non-minority subset expressed the stigma around early staged forms of cancer. There was an enigma surrounding the idea of their cancer being diagnosed early; therefore, many did not undergo the same cancer struggles that a person of a later diagnosis might have endured. There was a lack of resources when patients scoured for support for these earlier forms of cancer. Some patients did not feel they needed support due to the fact their journey was not as extensive. On the other hand, other patients wanted support during their journey because they underwent many physical and emotional battles while dealing with their early-staged cancer diagnosis.

Within the minority subset, there was a stigma about men being strong and emotionless in regards to their cancer journey. In reality, it was quite the opposite. A multitude of male participants felt like there was a lack of support groups surrounding men with cancer and had struggles finding support outside their close network of family and friends:

“Men don't go to the doctor. We don't talk about our issues. We don't want anybody to see our flaws. I think a lot of it could also be self-inflicted.... And the support that we could really have.... we're really not going to get the recognition, the sponsorships or the support until we take it seriously, man, and we open up and talk about our flaws and our vulnerabilities and our insecurities. Men need to move differently”

- African American, Male, 55, Prostate Cancer

Several male participants mentioned how they viewed this research interview as not only a form of support, but a great outlet to speak their truth because many were not asked about their experience with cancer; hence, many of their interviews possessed the longest interviewing durations within this study.

Within the minority subgroup, often times minority members were not properly heard regarding their health:

“It's like as minorities, we are not listened to. When we go to the doctor and tell them what's going on with us, they just sweep it up under the rug and then boom, later, here it is. We have cancer, we have diabetes, kidney failure because nobody listened to us”

- African American, Female, 52, Breast Cancer

Specifically among African American women, there was the "strong independent black woman" trope. This stereotype falsely depicted black women to be so strong and independent to the point

of not needing care due to their strong-willed and enduring nature (Subhan and Johnson, 2022). Many women from this demographic group have expressed how they were treated in regards to this stereotype and there was a common reoccurrence from many African American female participants regarding the negligence of their pain:

“When I went through my biopsy and the doctor said that she was limited by law in what she could give me, I believe that that really was her saying, "You're a Black woman. You can tolerate this pain.... There is this perception that we, as Black women, we're strong and we're tough and we can tolerate so much more. And I think that she just didn't want to be inconvenienced by going out and getting some more [pain medicine].... I don't know what she was giving me.”

- African American, Female, 62, Breast Cancer

Yet another stigma from the minority participants was the notion of not going to the doctor out of fear:

“People of color, they don't want to go to the doctor because they feel that the doctor's not gonna treat them correctly. Tuskegee counts as one of them will you know, it's a lot of people feel the that way, just like what happened with the COVID vaccine. Ohh, minorities felt that way and a lot of didn't get the shots because of they thought that the medical professions were, you know, were there to just, you know, run tests on them, see how they react towards the vaccine”

- African American, Female, 65, Breast Cancer

Among both participant groups, there was a universal stigma around being a cancer survivor and having "survivor's guilt". "Survivor's guilt" was the idea of being sympathetic towards other cancer patients, as well as, understanding that another individual's cancer diagnosis and journey could have been worse than their own:

“There's a little guilt there of like I don't really have cancer, but I do. There was a little guilt there like mine's not as bad as yours. I don't even want to say it to anybody. It is, but mine is very curable and I knew it up front and hers is potentially [worse]”

- Caucasian, Female, 61, Malignant Melanoma

It was also known that they viewed their cancer diagnosis as very minor in their grand scheme of life. As more time passed, they did not think of it extensively. There is also much apprehension around the idea of being a cancer survivor. Though the general public may see it as a badge of honor regardless of the cancer diagnosis and stage, not all participants considered themselves to be a survivor due to the ease of their cancer journey. They empathize with the fact other cancer patients may have a harder journey than themselves.

#### *Communication in Relation to Medical Staff*

As stated in the previously, more involved medical staff members influenced better cancer experiences from participants. Participants stated how they had better communication between more involved and engaged medical staff members:

“During the medical visits, there was always the willingness to stay and explain as much as I needed explained...During one of my infusions, one of the young ladies had the bubbliest personality, and she made you feel like you were the only person she was focusing on”

- African American, Female, 62, Breast Cancer

Contrastingly, other patients have expressed that their medical staff members were dismissive and rude:

“The doctor was irritated with me. It was something to the effect of, "this is not how we do it. We haven't had the review board," and I'm like, "I don't care. You have lab results that are about me and I want you to share them." She said, "here they are, and yes, it's cancer". I'm like, "okay, thanks." That was about it”

- Caucasian, Female, 58, Breast and Colon Cancers

While others have reported other patients that behaved poorly to further instigate the tension with their providers, some participants have expressed how medical staff members were very non-communicable and rude:

“I had the one oncologist that did not.... request the genome testing. The first one. He didn't ask for it. That's why he got fired. I made him ask for it, and then he never did. They lost the samples, and all that was on his watch. Then, I moved to a different one”

- Caucasian, Female, 58, Breast and Colon Cancers

thus, resulting in hindered care for their cancer treatment due to an overall lack of trust.

While many patients understood the medical terminology mentioned during their appointments, others were left confused and bewildered. A substantial number of participants agreed that certain medical professionals are aware of their behavior:

“Medical professionals of a certain age are aware and they don't care. I think that younger professionals are less about their ego and God-mentality and really more about making sure that the patient understands and is a part of their treatment”

- African American, Female, 62, Breast Cancer

In agreeance, few patients have expressed how their physician was "stuck in their ways" and "unwilling to listen" to their concerns because "the lab results stated otherwise"; whereas, a large majority of participants also believed medical professionals were accustomed to repeatedly communicating using medical jargon and were oblivious to how their patients actually felt.

In accordance of how many participants believe medical staff members were unaware of how the medical jargon they utilized around their patients made them feel, other patients had high levels of comfortability around usage of medical terminology due to their careers or their higher level of education in health-related fields. Few participants believed that there was a difference in



communication, as well as the level of treatment they received, based on their occupation and education level; therefore, they believed they received a form of preferential treatment.

Few non-native English-speaking participants have expressed insecurities in communication with their medical professionals due to the language communication barrier. They have recalled how their physician spoke to them in a condescending manner:

“My experiences with healthcare...I didn't really trust doctors so much, and it was because of experiences I had when I was a kid growing up, experiences I've seen my parents go through with their doctors. And then now you know, the other experiences that I've had now with the cancer journey.... it's kind of been hit or miss.... I've been dismissed a couple of times. I did pass a negative judgment on doctors a lot because of that. The way I've been dismissed, the way I've seen people in my family been dismissed... I did pass a negative judgment on doctors a lot because of that. The way I've been dismissed, the way I've seen people in my family been dismissed”

- Hispanic, Male, 53, Prostate Cancer

Ultimately, they are told and left to "deal with it" themselves.

### *Physical /Emotional Impact*

Almost all participants in this study have reported mental health issues of both anxiety and depression, but luckily, nearly all participants learned to self-advocate for their health. Once many

participants learned that their health was in a fragile state, they placed more importance and prioritization on their well-being. While some participants had a painless cancer journey, other participants have expressed the physical effects of their cancer treatment, effects of radiation, and the effects of cancer medicine.

After enduring these painful experiences, many individuals have reported jaundiced and jaded feelings about their cancer diagnosis. While other patients “have heard some of them [patients] have a nasty attitude”, these patients have also barraged their medical team members and “need to correct themselves”. In retaliation, medical staff are more defensive in their treatment to the patient; therefore, their professional relationship and bond has suffered.

While many participants openly accepted the reality of their cancer diagnosis, a few participants were in denial about their entire situation. Nearly all participants expressed concerns of fear. Fear was the most common pattern among all participants:

“I was stunned. I couldn't believe it. I thought it had to be a mistake, that maybe it was just another cyst and it was just being misdiagnosed... I may die 'cause back then, I don't think we ... No, we didn't have a technology and medication for the cancer. I didn't think I was going to live very long, maybe a few years”

- African American, Female, 73, Breast Cancer (DCIS)

7 participants (5 minority and 2 non-minority) had a reoccurrence of their cancer and unfortunately, 1 participant succumbed to the disease. Feelings of fear about the diagnosis were frequently coupled with paranoia. More than 3/4ths of the participants were overly cautious that their form of cancer would make a reoccurrence down the line in their future:

“After cancer, you still have those residual effects. I have that PTSD that will come back. I do have those scares. As you know, I'm very vulnerable to cancer. It's at the forefront”

- African American, Female, 44, Breast Cancer (DCIS)

Contrastingly, few patients felt relieved once their cancer reappeared:

“When it comes back that second time, you're relieved. Now, I can embrace it. That's why I'm sitting here with you, because now I know it's real. Before, it's like, what the hell? Now, that it came back, it's real”

- African American, Male, 49, Non-Hodgkin's Lymphoma (Large B-Cell Lymphoma)

After the intermittence of cancer, the feelings of constant paranoia transformed into relief because the chance it would return loomed their subconscious mind, and eventually came to pass.

Many participants happen to be parents themselves. Few of participants decided to conceal their cancer diagnosis from their close friends and family before eventually telling them the unexpected news. Luckily, through the support from the close family members and friends, they were encouraged to keep advocating for their health.

Regarding the male participants, it was noted that they were not properly validated and comparison to their female counterparts. Many men struggled to find support groups and seek resources within their own personal life:

“My wife saw an article on him [a friend’s support group] in the Marietta Daily Journal and I believe in AJC as well. So at that time I was just kind of lost and I thought it was that time to reach out because he had a similar story to me. So that was another step that I took is support, how am I going to get through this or what do I need to do? I need to build my support. I need to understand this more.... that was another important step, reaching out. So that's another thing too is doctors really don't promote things like that”

- Hispanic, Male, 43, Prostate Cancer

### Unique Experiences

Within the minority participants, there were higher instances of unique experiences. 89% of participants from the minority group accounted for enduring unique experiences; whereas, 53% from the non-minority group had unique experiences. Unique experiences are categorized as abnormal or unexpected events that occurred during their cancer journey and treatment, exclusive to that individual. Such events are rare in comparison to the average cancer journey anecdotes of other participants. One participant recalled how she was given the wrong medicine and her medical team took no regards to fix the problem. Her medical team ignored her cries and denied her, her proper medicine; therefore, her body reacted poorly to the cancer medicine, as she previously explained to them about her side effects.

An additional participant explained how the treatment from her medical doctor and his staff caused trauma; thus, causing her to abandoned her cancer treatment, despite the fact their office did not bother to remind her about her appointments:

“Really [this experience] stuck with me that he did not care anything about me being a breast cancer patient. And he didn't finish my treatment. So I had to go all this time. I went months from March till September with no treatment from a doctor. So I had to reach back out to the doctor who did my original breast reduction, even though he didn't have anything to do with it. But he felt so bad that this happened to me. But he found me a doctor”

- African American, Female, 53, Breast Cancer

Another participant, who had previous struggles in his previous past with drug usage, stated:

“Respondent: This fake-ass doctor, Dr. Death I'm call him, said that I refused treatment and I never knew who the hell this man was. Only thing he said is, "How you doing?". I said fine and everything, and this other Black doctor came in. I'd never seen him before, and he said, "Why did you refuse treatment? Dr. Such-and-such said you refused treatment because you've got a heart condition." I said, "I ain't even know I had a heart condition", so they rushed me out and sent me down to main campus.

Interviewer: So the doctor lied and said that you refused treatment, but the truth is you didn't even know what you were being treated for because they never told you that you had a heart condition?

Respondent: Exactly! Because I was an addict, he said why should I care. Eventually, what did he say? Well, I don't give a fuck. I'll let his ass die. That's what the bottom line was”

- African American, Male, 62, Lung Cancer

Lastly, a survivor explains how a doctor botched her recovery surgery and neglected her call to attention about her surgical site, which become infected with a severe case of gangrene due to a serious infection. While these experiences were quite unique to the minority demographic of participants, it was reported that after self-advocating and making the proper health care changes, whether it be changing practices or switching primary providers, nearly all participants appreciated their medical staff members.

## **Discussion**

Within the subset of minority participants, the findings concluded there were many experiences accustomed to their journey. This collection of participants had the largest ranges for both the age at diagnosis (ages 19-86) and age at the interview (ages 25-89), with the youngest participant being 19 yrs. and oldest participant being 86 yrs. A very common stigma among younger cancer patients was the notion that because of their juvenile age, they were deemed able-bodied and free of health issues. Unfortunately, cancer is a non-discriminatory disease. Likewise, due to the fact that an individual may have appeared perfectly healthy, they may have been battling diseases unbeknownst to the human eye. Unfortunately, there were many negative stereotypes associated

with older age cancer patients (Levy *et.al*, 2022). They were considered more fragile, more non-compliant, slower to recover from injury, in poorer health, as well as a possible inconvenience to family members and caretakers. Due to these negative perceptions, it can be inferred there was a possible natural implicit bias among healthcare employees to dismiss and overlook the health needs of older patients. While these negative connotations may not be the reality for all practices, it is paramount that medical professionals are giving quality and non-discriminatory care to older patients, as they do younger ones. To debunk the stigma that cancer only happens when to older individuals, it should be noted that cancer does not discriminate. Though it is true that as an individual develops in age, there is an increased likelihood of developing cancer due to the accumulation of free radicals and toxins within their body, individuals from all walks of life are impacted by various forms of cancer.

Among the male participants, findings indicated that many men have expressed repressed feelings regarding their experience with cancer. With the most extensive interview lasting over two hours, it was taken into consideration that male participants had longer time durations for interviews. As expressed earlier, many male participants' have mentioned this interview as part of their only outlet for support because they did not have avenues for support or therapy. There was much speculation that due to many societal norms placed upon men, such as the ideology of men being emotionless and detected from their feelings, many male participants expressed how their feelings were repressed during their cancer journey. Many have blocked their internalized feelings in order to move forward with this battle; whereas, others have diminished their feelings to the point they almost forgot they had cancer. It can be implied that due to the societal ideology for a man to hide his emotions and "deal with it", men have been taught to hide their true emotions and deal with their own personal struggles in privacy. Doing so aids in the lack of knowledge about

support groups catered to men because of the looming absence in the exchange of information among this demographic.

The "strong independent black woman" trope was an additional stigma found, specifically among African American women in the minority subgroup. This negative caricature eventually leaked into medical practices and unfortunately, it was a reoccurring concept that black female participants received less than adequate medical attention regarding their pain and cancer treatment because they were categorized as "the strong, independent black woman" (Woods-Giscombé, 2010; Mathur *et al.*, 2014; Subhan and Johnson, 2022). Due to the systemized stereotyping of black women, there were increased reporting's of unique experiences from their cancer journey, aligning with the increased amount of unique experiences in association with minority participants. This trope negatively impacted African American women because they were regarded as almost subhuman, inferring that their pain tolerance levels were higher or nonexistent in comparison those of other races (Mathur *et al.*, 2014). The results from the TikTok prompt demonstrated that the replies from minority cancer survivors also coincided with the unique experiences from other minority participants. There were heightened amounts of unique experiences in the minority population of participants and instances like these further perpetuate the ideology to avoid seeking medical attention. The multitude of unique experiences from the minority demographic of participants further reinforced the fear of seeking medical attention. In efforts to improve the treatment of more minority patients, there should be more reform within the healthcare system to accommodate their needs.

The results demonstrate a frequent barrier to seeking medical attention originates from underlying fear. From non-native English-speaking participants, there were possible communicative barriers that impacted the level of communication and comprehension. Due to this



communicable disconnect and possible acts of discrimination, the lack of communication created further miscommunication; thus, resulting in hindered care for their cancer treatment (Steinburg *et al.*, 2016). There was much reluctance around asking for help because often times there was miscommunication and a lack of understanding from their medical professionals (Steinburg *et al.*, 2016). As a result, patients felt inferior; therefore, they shied away from engaging in communication with their providers. As a way to combat this social determinant of health, medical providers can begin using medical interpreters to effectively communicate information relayed from one party to the other. Additionally, some participants felt discriminated against because of their cultural background by their medical professional; therefore, they did not feel comfortable seeking medical care. It can be inferred that the medical staff member had pre-existing biases regarding caring for patients from non-native English-speaking countries but it also further reinforced the negative stigma of minority subgroups being fearful of seeking medical care. These fears often derived from the pre-existing history between minority communities and the medical field, as well as, preceding encounters with doctors/medical staff. It was recognized that many medical staff members have expressed a lack of concern for the health of their patient; therefore, there was no reason for the patient to regard the medical staff member as a trusted entity. As a result of these forms of internalized trauma, many patients have decided to take matters in their own hands or abandon the quest to find a better health provider. To combat the avoidance of medical attention, more trusted and diverse medical staff members are needed. Other medical professionals could also benefit from seminars about better patient-centered care for cultural diversity patients.

There have been many technological advancements to aid in cancer prevention services/screenings. The proper supervision of staff technicians and the correct training of medical equipment deserved attention, as well. Although many strides were made to increase survivability rates of cancer survivors, there is a need for more sufficient technology to improve the chances of detecting cancer more efficiently and at earlier rates. Often times, there was miscommunication and ambiguity around an inconclusive medical scan; therefore, many medical professionals wrote off their cancer abnormality as a minor scare instead of further investigating into the issue. Even with the slightest hesitation or reluctance, it is paramount that these findings are noted and further investigated for any malignancies for the sake of the patients' health. From both subgroups, findings demonstrated a distinguished number of early-staged participants mentioned "survivors' guilt" because their journey was almost minute in comparison to other cancer patients with later staged cancers. Others did not want "another label put on them" nor to have to think about their journey consistently, so they also rejected the title. Depending on the level of involvement in care from medical providers, patients went to their physician for information about their cancer diagnosis. These experiences drastically varied depending on how involved the medical staff member was in their cancer journey. Patients were more receptive to information from more involved medical staff members, were more likely to communicate their needs efficiently, and overall had a greater experience with their cancer journey. A possible theory includes the idea that physicians saw a reflective image of themselves in some of their patients; therefore, they became more attentive to their care and there was a strengthened bond in communication because the provider was more involved. Due to the strengthened bond between the medical provider and their patient, it is inferred that the patient was more likely to actively have an open line of communication with their provider and openly seek/accept their medical advice. On the other hand,

it was known that the lack of communication created further miscommunication. Dismissive behavior from physicians and other medical staff members created resentment within the patient because their health is overlooked. Encounters such as these created notions that their health was not a priority; therefore, they completely avoided communication with their medical staff. Based on their provider to patient bond, patients could have felt comfortable with asking additional questions or completely shunned the idea for further explanation. Though physicians care for patients from very diverse backgrounds, unfortunately, not all patients were allotted the same amount of respect and care for their cancer treatment. Participants from both subgroups believed the dismissive form of communication stemmed from possible superiority complexes within medical providers and their staff members. As a counter to disobliging medical staff members, who resist listening to their patients' needs, participants as a whole have learned to self-advocate for themselves. In efforts to take full control of their cancer journey, many participants in this situation have resorted to switching medical providers in hopes of a better experience. During the duration of this study, 7 people did not attend their interview and one person withdrew their consent from the study. The statistics can infer there was possible embarrassment and fear about sharing the truth about their cancer journey. These feelings to denial could originate from for internalized feelings of embarrassment for getting this disease. A couple of parents, especially male parents, were embarrassed to inform their loved ones about their diagnosis because they were expected to uphold the strong matriarch/patriarch role of the family. While they may have felt embarrassed to inform their children of their diagnosis, they leaned on their children for support during these hard times and use their children as a reason to fight harder against their cancer battle. Through these entities of support, participants were able to listen to their advice firsthand and learn more about their diagnosis through their vicarious experiences. This was very concurring with the importance

of how engaged medical staff members have an influential effect on their patients and their cancer journey. Overall, both groups of participants agreed that treatment was expensive. It was very crucial to have healthcare insurance and a well-paying job to help offset any financial risks from cancer treatment services. Though having to navigate around work in order to receive cancer treatment seemed tiresome, many participants needed the income for their family. These were some of the tough decisions that cancer patients faced, especially those that encountered many disparities in order to receive treatment. Members from both groups expressed lack of knowledge about cancer. Due to this lack of information, their diagnosis was delayed because they were not taught the proper way to seek medical attention. This lack of knowledge also facilitated the deficiency of preventative methods. Participants did what they could at the time with the information they had and attempted to make the best of their diagnosis. Now that participants were fully aware of the cancer resources available to them, they have broadened the scope of information so others are knowledgeable. During these times of struggle, many participants sought guidance and emotional support from their religion. Due to this guidance, participants decided to "turn their life around", do more acts of servitude, and to actively seek God for life improve. Few participants expressed how their health was almost perfect and they followed all the health reminder; yet, they were still diagnosed with cancer. One of the most common questions was, what can we do to prevent cancer? Alas, we live in a very carcinogenic world where toxins have plagued the environment. At this point, who becomes diagnosed with cancer is almost a luck of the draw. Fortunately, now that we are more knowledgeable and have access to preventive screenings/measurements, we are able to detect cancer earlier to aid in the increased survivability rates.

The results indicated that while there were many different themes among non-minority and minority participants, there are many overlapping themes as well. Participants from the minority subset tend to have more unique cancer experiences and instances of ignored health problems compared to the non-minority group. My minority participants also had a more elevated age range bracket for their initial cancer diagnosis compared to the non-minority subset. Based on findings from the male participants, there was more of a noticeable difference between treatment given to female patients. Male participants were less likely to receive a good support system compared to female participants and did not have any avenues to express their innermost feelings. It can be inferred that the societal norms placed upon men not expressing their feelings is denoted by the repressed and internalized feelings from their cancer journey. Results from the study also demonstrated that while there were many gaps in communication between healthcare providers and their patients, many medical staff members were willing to fully explain their diagnosis to their patients. It was noted that highly involved and motivating healthcare staff were correspondingly more influential on their patients and encouraged a more enjoyable cancer experience. For medical professionals that were not as open in their communication, patients researched on recommendable websites from the internet and utilized friends/family for direct sources of information. Lastly, while it can be assumed that many consider themselves to be a "cancer survivor", there were mixed emotions around the title of being a survivor. Many participants expressed having "survivors' guilt" because their diagnosis could have been worse in comparison to other cancer patients/survivors; therefore, they did not exactly consider themselves to be a cancer survivor. On the contrary, there were many that consider themselves to be a cancer survivor based on the magnitude of their cancer journey.

### Limitations

The limitations of this study were congruent as with all qualitative data; interviews/results all data is self-reported and are non-verifiable, meaning we must take the participant's word for face-value regardless of their true or covert feelings regarding the subject matter. The time restraints on this research study was another limitation. Subjectively, the TikTok prompt video was not uploaded long enough to get an optimal amount of replies. An additional limitation of this research focused on avoiding any bias; instead, identifying the full picture detected by the modified grounded theories approach. Though this research is a stepping stone to make improvements in cancer research regarding treatment and patient care, this subset of interviews does not adequately represent all cancer patients as a whole. It is non-generalizable. Sample sizing was significant, yet, not influential enough to be exploratory for data within a thesis. I would like to explore more about income in relation to cancer experiences and the vast experiences from members of the LGBTQ+ community. It should also be priority to continue research upon the lower income participants; whereas, the subset of participants lied predominantly within the middle to upper class population, with higher levels of education. Due to the lack of access that lower income individuals have, they don't have the resources to receive the care they require. This is indicative of a possible middle-class phenomenon for middle class individuals to get earlier stages of cancer due to level of care and access to care. In conjunction with the promotion of this research in the future, more participants are needed to further explore these themes.

### **Conclusion**

In conclusion, due to the technological advancements in cancer research, early-staged and curable cancer diagnosis are becoming more prominent. Though these technology advancements have helped detecting the early cancer, there have been more lasting emotional impacts in regards to their cancer journey. Both non-minority and minority participants had numerous amounts of equivalent themes and disparities regarding their cancer journey; however, minority participants reported more disparities and themes. Though cancer does not discriminate, there were varying differences in treatments and unique experiences among minority and non-minority participants. Minority participants underwent more unique experiences compared to their non-minority counterparts. While more male participants appeared stoic and indifferent about their cancer journey, many discussed expressions of fear, doubt, and paranoia from their experiences. Male participants also received less support compared to their female counterparts and were expected to handle their own emotional and physical effects from this experience. While there were major gaps in communication among medical professionals and their patients, there was a strong correlation between having very involved medical staff and having a greater cancer experience. In juxtaposition, having less involved medical staff caused patients to have a tainted and intolerable cancer journey; however, there were increased rates of self-advocacy and yearning for more knowledge due to the lack of knowledge and the prioritization of one's health. Implications from my results suggest the need for more involves staff members, which are necessary for improved patient care. It was recommended to implement mandatory workshops, seminars, and additional training services to optimize patient care measurements and customer service skills.

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## Appendix: Interviewing Questionnaire

### 1. **What is cancer?**

- a. How do you define cancer?
- b. What does cancer mean to you?
- c. How did you arrive this understanding of cancer? What did you think about cancer before cancer versus afterwards?

### 2. **How did you first realize that there was a problem?**

- a. Describe your early symptoms. How were you feeling?
- b. What made you seek medical attention?
- c. Or did you find out through routine screening?
- d. How did you decide that this was something serious?
- e. Timeline between symptoms/screening → diagnosis → treatment → cancer-free/cure

### 3. **How were you diagnosed with cancer? Describe the chain of events.**

- a. What types of diagnostic tests did you have?
- b. How long did it take for you to be diagnosed?
- c. What did your doctor first say about your diagnosis?

- d. How were you feeling when you received your diagnosis? What was going through your mind at the time?
- e. What do you think could have been done differently?

**4. Becoming a “cancer patient.”**

- a. What were your initial thoughts after the diagnosis?
- b. What were your initial actions after the diagnosis?
- c. Whom did you tell and how? What did others think/how did they react to your news?
- d. Where did you go for more information?
- e. Where did you go for support?
- f. Did you think of yourself as a cancer patient? Explain.
- g. How do you think you compare to other cancer patients?

**5. How was your cancer treated?**

- a. Did you seek a second opinion?
- b. How were the treatment options presented to you?
- c. How did you feel about these options?
- d. How was your prognosis/cure described to you?
- e. How did you feel about your prognosis/cure?
- f. How long did your treatments last?

- g. What side effects did you experience (physical or emotional)?
- h. Did you receive any ongoing support during treatment?

**6. How as your cancer been followed?**

- a. How often have your received follow-up care?
- b. How do you feel about going to the oncologist?
- c. What do you think about your follow-up plan? Does it make you feel better or more stressed?
- d. How do you feel as more time passes after your experience with cancer?

**7. Living After Cancer**

- a. How has cancer affected you?
  - i. Positively
  - ii. Negatively
- b. What do you tell people about your cancer experience?
- c. What do you want people to know about cancer?
- d. What advice would you give someone who found themselves in a situation similar to yours?
- e. How can people protect themselves from cancer? Have you made any changes to your life?
- f. What would you say to your healthcare providers?

- g. Do you view yourself as a “cancer survivor?”
- h. Do you participate in cancer survivor activities? Explain.
8. Tell me about any times you felt like you weren't heard by medical professionals?
9. Describe times medical professionals went above and beyond for your medical needs?
10. Can you tell me about the times medical professionals used words or medical language that you didn't understand and you needed them to explain it further?
11. Describe any experiences, whether good or bad, that stuck with you?
12. Can you tell me in which way you think your cancer treatment and journey could have gone differently?
13. Explain the stigma around medical care and minority /underrepresented communities?
14. Can you describe times you felt like there were some personal biases medical professionals were projecting onto you?
15. Can you explain if you personally think there's a difference in treatment between minorities and non-minority cancer patients?

**Need to know:**

- Current age
- Age at dx
- Time since dx

- Type of cancer
- Treatment type (surgery, radiation, medications (not traditional chemo))
- Zip Code
- Gender
- Race/ethnicity
- Marital status
- Educational level
- Employment status
- Number of children