

**Black and African American Lived Experiences of Stroke**

by

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Bachelor of Philosophy, University of Pittsburgh, 2022

Bachelor of Rehabilitation Science, University of Pittsburgh, 2022

Submitted to the Graduate Faculty of the  
School of Health and Rehabilitation Sciences in partial fulfillment  
of the requirements for the degree of  
Bachelor of Philosophy

University of Pittsburgh

2022

UNIVERSITY OF PITTSBURGH  
SCHOOL OF HEALTH AND REHABILITATION SCIENCES

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People who are African American have a greater propensity for stroke, sustain more severe disability, and experience less functional recovery compared to people who are White. However, the experiences and perspectives of this population have not been thoroughly explored. This study explored perspectives about stroke, healthcare, and rehabilitation among people who are African American and sustained a stroke. We conducted 13 semi-structured interviews examining the perspectives and experiences of adults who: (1) identified as Black or African American and (2) sustained a stroke at least 3 months prior to the interview. Participants were recruited through electronic advertisements on social media sites, presentations at local support groups and rehabilitation centers, university research registries, and previous stroke rehabilitation studies. Interviews were transcribed verbatim and checked for accuracy before undergoing coding and thematic analyses conducted by a team of rehabilitation and health disparity scientists. Four major themes emerged: 1) *Intersectionality of Race, Health, and Healthcare*, 2) *Healthcare Access, Quality*, 3) *Provider Interactions and Communication*, and 4) *Tensions Between Expectations and Experiences*. Multiple sub-themes pertained to provider-patient listening and understanding, trust, education, and patient and family agency, as well as cultural norms and autonomous decision making. Major themes and sub-themes draw awareness to and educate healthcare professionals on the nuanced experiences of African American people after stroke; and point to focused strategies for provider training, community education, and improved healthcare access and quality to be more responsive to the needs of this population.

## Table of Contents

<b>1.0 Background and Rationale.....</b>	<b>1</b>
<b>2.0 Methods.....</b>	<b>5</b>
<b>2.1 Study Design and Procedures.....</b>	<b>5</b>
<b>2.2 Data Collection.....</b>	<b>6</b>
<b>2.3 Data Analysis .....</b>	<b>9</b>
<b>3.0 Results .....</b>	<b>10</b>
<b>3.1 Participants .....</b>	<b>10</b>
<b>3.2 Summary of Thematic Findings.....</b>	<b>12</b>
<b>3.3 Major Theme 1: Intersectionality of Race, Health, and Healthcare .....</b>	<b>14</b>
<b>3.4 Major Theme 2: Healthcare Access and Quality.....</b>	<b>15</b>
<b>3.4.1 Healthcare Access .....</b>	<b>15</b>
<b>3.4.2 Healthcare Quality .....</b>	<b>17</b>
<b>3.5 Major Theme 3: Provider Interactions and Communication .....</b>	<b>18</b>
<b>3.5.1 Listening, Understanding .....</b>	<b>19</b>
<b>3.5.2 Trust, Perceived Bias .....</b>	<b>20</b>
<b>3.5.3 Patient, Family Agency .....</b>	<b>22</b>
<b>3.5.4 Education on Prevention and Recovery .....</b>	<b>24</b>
<b>3.6 Major Theme 4: Tensions Between Expectations and Experiences .....</b>	<b>26</b>
<b>3.6.1 Atypical Presentation, Disbelief.....</b>	<b>26</b>
<b>3.6.2 Gender and Cultural Norms .....</b>	<b>28</b>
<b>3.6.3 “Ups and Downs” of Stroke Recovery .....</b>	<b>28</b>

<b>3.6.4 Health Management Choices and Implications.....</b>	<b>31</b>
<b>3.6.5 Autonomous Decision Making .....</b>	<b>32</b>
<b>4.0 Discussion.....</b>	<b>33</b>
<b>5.0 Conclusion .....</b>	<b>39</b>
<b>Bibliography .....</b>	<b>40</b>

## List of Tables

<b>Table 1: Interview Questions .....</b>	<b>7</b>
<b>Table 2: Participant Characteristics .....</b>	<b>11</b>

## Table of Figures

<b>Figure 1: Summary of Thematic Findings.....</b>	<b>13</b>
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## 1.0 Background and Rationale

Stroke is a leading cause of disability in the United States. Improvements in stroke rehabilitation are contributing to improvements in functional outcomes and quality of life for people who have sustained stroke; however, these trends are not sustained among the African American population. People who are African American have a greater propensity for stroke, sustain more severe disability, and experience less functional recovery compared to people who are White (Ellis et al., 2015). Biological differences fail to explain the inequities in stroke recovery between White and minority populations (Burke. et al., 2014), so there must be other contributing factors. To understand these differences in outcomes, it is necessary to examine each population's experiences in depth. However, the experiences of people who are African American and who have had a stroke have not been thoroughly explored in the current published literature. It is imperative that we delve into the experiences of those who are African American to explore their perspectives about stroke, their healthcare experiences, and their rehabilitation. In doing so, these investigations may provide insights into potential factors that influence stroke and rehabilitation recovery for people who are African American. By examining experiences before, during, and after stroke, people who are African American can have a voice in the design and delivery of their healthcare and rehabilitation to best suit their needs.

This research will expand the very limited literature that explores the specific experiences of people who are African American and have had a stroke. Qualitative research studies suggest that people who are African American have limited access to preventative healthcare and community resources, likely contributing to a higher propensity for stroke, as well as limited access to high quality acute medical and rehabilitation treatment options (Ellis et al., 2015).

Furthermore, people who are African American are more likely to be uninsured or underinsured and live in communities that are less likely to have stroke medical and rehabilitation centers of excellence. These communities are also less likely to have community resources to support people with stroke-related disability as they re-enter the community. Thus, it is not surprising that health services research studies demonstrate that people who are African American are significantly more likely to be discharged to home than referred to medical or rehabilitation specialty services and are significantly less likely to have good functional outcomes after rehabilitation compared to matched White participants (Cruz-Flores et al., 2011). These studies point to just some of the elements of structural racism experienced among African American people who have had a stroke. Such structural racism contributes not only to the stress that increases the likelihood of stroke among the African American population, but also contributes to the ineffectiveness of stroke medical and rehabilitation intervention delivery in this population (Magwood et al., 2019).

However, these structural barriers are not the only contributing factor (Cruz-Flores et al., 2011). There is a need for education to address limited knowledge about stroke signs and symptoms, the importance of timely administration of interventions, and the benefits of rehabilitation services and community activities after stroke. This education needs to be tailored to meet the needs and context of people at high risk. Without tailoring and sensitivity to the specific needs of people who are African American, administration of education, treatment, and rehabilitation will have dampened effects (Eisenstein et. al).

Healthcare providers across the continuum are not well-educated in the nuances among different cultures (Magwood et al., 2019). Communities of people who are African American have their own belief systems, gender roles and norms, family dynamics, and many other cultural factors that influence their use of healthcare and their perceptions of illness and disability (Eisenstein et

al., 2018). Furthermore, stroke-related disability often directly interferes with participation in community groups, families, and cultural activities, and if not addressed leads to restricted participation that often compounds post-stroke depression and worsening functional outcomes (Blixen et. al). If providers are not informed in the cultural context of their patients, they cannot tailor their services to meet patients' needs. Without the active acknowledgement of and education in differing cultural beliefs, providers will never be able to effectively treat the physical and mental needs of people who are African American after stroke.

There is a myriad of factors that may contribute to the higher incidence of stroke and stroke-related disability among people who are African American. Most of these factors cannot be easily quantified or explored without a deep dive into the experiences and perspectives of people who are African American and who have experienced stroke. Qualitative studies that compile and deeply explore the stroke experiences of people who are African Americans are needed to draw awareness and inform education, treatment, and rehabilitation efforts.

To explore these issues, we conducted semi-structured interviews with people who are African American and who have experienced a stroke to examine the following research questions:

- 1) What are the overarching themes among research participants' interviews with respect to personal perspectives and experiences of stroke and recovery?
- 2) What are the overarching themes among research participants' interviews with respect to perspectives and experiences of primary, pre-hospital, hospital, and rehabilitation care in relation to stroke prevention, treatment, and recovery?
- 3) What are specific suggestions for improvement participants had to improve the healthcare quality for those who are African American and have had a stroke?

Findings from these interviews can be used to inform the development of rehabilitation interventions and services that tailor provider-patient interactions, reduce stroke-related disability, and improve recovery among minority populations.

## **2.0 Methods**

### **2.1 Study Design and Procedures**

We conducted 13 semi-structured interviews examining the perspectives and experiences of adults who: (1) identified as Black or African American, (2) sustained a stroke at least 3 months prior to the interview, (3) were community dwelling, (4) were willing and able to provide informed consent, (5) were able to participate in a conversation using English, and (6) did not have a physician diagnosis of dementia. Participants were recruited through electronic advertisements on social media sites, presentations at local support groups and rehabilitation centers, university research registries, and previous stroke rehabilitation studies. For most recruitment resources, information was disseminated to potential participants and interested participants contacted the research team by telephone, email, or social media. For one recruitment resource, the University of Pittsburgh Claude D. Pepper Center Community Research Registry, the first author searched the database for potentially eligible participants and contacted these individuals, per the approved protocol. Once participants verbalized interest in the study, the first author (JA) arranged a telephone conversation to provide a description of the study and to obtain informed consent. Those who provided informed consent were then screened for eligibility. Eligible participants were individually scheduled for a one-hour interview conducted by the first author (JA) via telephone or web conference. After the completion of the interview, participants filled out a questionnaire to gather information not obtained in the one-hour interview.

Those who completed all study activities (interview, questionnaire) received \$25 remuneration for their participation. All procedures were approved by the University Institutional Review Board (STUDY 20120068).

## **2.2 Data Collection**

The authors created the interview guide through a series of team meetings. The first author was an undergraduate rehabilitation science student at the time of this study with experience in qualitative research. The remaining authors are experts in qualitative research (JH, LW), stroke and gerontological rehabilitation (JH, JB, ES), and patient and family stakeholder engagement (TH, LW) methods. Among the authors were one undergraduate rehabilitation science student (JA), two occupational therapy scientists (JH, ES), one physical therapy scientist (JB), one peer mentor and patient advocate (TH), and one community health advocate with expertise in healthcare disparities and inequities in marginalized and underrepresented populations (LW). The research team was comprised 6 women, 2 who identify as African American (TH, LW), 1 who identifies as Middle Eastern (JA), and 3 who identify as White (JH, JB, ES).

Prior to data collection, the first author conducted a practice interview with a co-author who is a peer mentor and patient advocate, is African American, and has had a stroke (TH). The purpose of the practice interview was to gauge the clarity of the primary interview questions and to practice conducting an interview. No data were retained from this interview. Based on this practice interview, the first author adjusted the interview guide. For example, the question “What do you want to see come out of this research?” was added as the research team was interested in learning what participants viewed as the most urgent matters that they wanted to be addressed.

These adjustments to the interview questions and the rationales were documented in field notes in the form of memos that were vetted by the co-authors.

**Table 1: Interview Questions**

1. What are the common beliefs about healthcare and stroke in the groups you most identify with? By groups I mean your family, those of the same race as you, church groups, or any other community you are a part of.
2. Tell me about your stroke story. What was your experience? I am interested to hear about anything you feel you want to share.
3. What was your experience with healthcare before your stroke? Are there any overwhelmingly negative or positive experiences you remember?
4. What was your experience in the hospital during and directly after your stroke? Are there any overwhelmingly negative or positive experiences you remember?
5. What was your experience with stroke recovery and rehabilitation? Are there any overwhelmingly negative or positive experiences you remember?
6. Do you have any advice for future healthcare providers in training?
7. What would you want to see come out of this research that listens to your experiences?
8. Is there anything else you would like to share with me about your story?

Through a one-time, 60-minute interview, the first author used a grounded theory approach to ask grand tour questions (**Table 1**) using an interview guide. At the beginning of each interview, the participants were reminded of the goals of the research study and the background for specific questions, including: (1) the need to explore why those who are African American are more likely to sustain stroke and more severe disability after rehabilitation compared to other groups, (2) the importance of learning from and listening to the experiences of those who are African American, (3) and the intention of listening to advise on how to tailor healthcare to best fit the needs of African Americans. Then, the first author proceeded with the grand tour questions. Participants were asked about their beliefs about healthcare and stroke, healthcare experiences prior to and after stroke, provider interactions throughout the continuum of care (acute hospital, rehabilitation services, and follow-up care), and transition to community after stroke. Participants were also given the

opportunity to provide advice that they wanted to give to future healthcare providers, and changes that they wanted to emerge from these interviews. Interview responses were audio-recorded and transcribed verbatim using Zoom (5.10.1, San Jose, CA) by the first author (JA).

At the end of the interview, participants were sent an electronic link to complete a demographic survey and questionnaires. The demographic survey gathered personal characteristics including race and socioeconomic information, social support, and specific healthcare utilization. The questionnaires comprised three measures used to explore potential barriers to recovery that were not discussed in the interview and to evaluate the participants' perceptions of the impact of racism in their lives and: (1) the Perceived Stress Scale, (2) the Perceived Racism Scale, and (3) the Discrimination Scale. The Perceived Stress Scale is a 5-item scale examining the thoughts and feelings of stress participants experienced over the previous month (Cohen et al, 1983). Each item is scored on a 5-point scale (1 – 5), with higher scores indicating higher levels of stress. The Perceived Racism Scale is a validated 17-item checklist of common racism scenarios often experienced by those who are African American. (Vines et al., 2001) The number of checked items is summed to obtain a score, with higher scores indicated more experiences of perceived racism. The Discrimination Scale contains 6 questions about common examples of discrimination experienced by those who are African American (Williams et al., 1997). Each question is rated on a 6-point scale (0 – 5), with higher scores indicating more frequent instances of discrimination encountered daily life.



### **2.3 Data Analysis**

The first author uploaded transcribed participant interviews in NVivo QSR Software (QSR International Pty Ltd. (2020) NVivo (released in March 2020)) for coding and thematic analysis. Qualitative analyses included the construction of a codebook, both an a priori version and a refined version after full completion of coding. The first author was the primary coder, but all codes were vetted by at least two authors and examined for triangulation. Variances were resolved by a third author. After the completion of data collection, codes were compared across interviews to develop common themes. Themes were vetted by at least two authors, and variances resolved by a third author. Transcribed interviews and thematic summaries were returned to participants for member checking after completion of data collection and analysis to confirm the accuracy of responses and interpretations.

## 3.0 Results

### 3.1 Participants

The study team received inquiries from 16 potential participants through previous contacts and the University of Pittsburgh Pitt+Me Research Registry and identified an additional 14 potential participants from the University of Pittsburgh Claude D. Pepper Center Community Research Registry. The first author was successful in contacting 20 potential participants from these initial recruitment efforts, 7 declined participation due to lack of interest or inability to commit the time once the study was described, and 13 provided informed consent. All participants who provided informed consent were eligible. Out of the 13 eligible participants, 11 completed both the interview and questionnaire and 2 completed the interview but not the questionnaire. Participant characteristics are displayed in **Table 2**. All participants identified as Black or African American and sustained a stroke at least three months prior to the interview. Local research registries were the primary recruitment source. One participant had a relationship with members of the research team prior to the current study. Due to convenience sampling, the participant population was skewed towards those with higher education. The intended number of interviews was 15 to 20. However, we achieved saturation of themes with 13 completed interviews in 7 months.

**Table 2: Participant Characteristics**

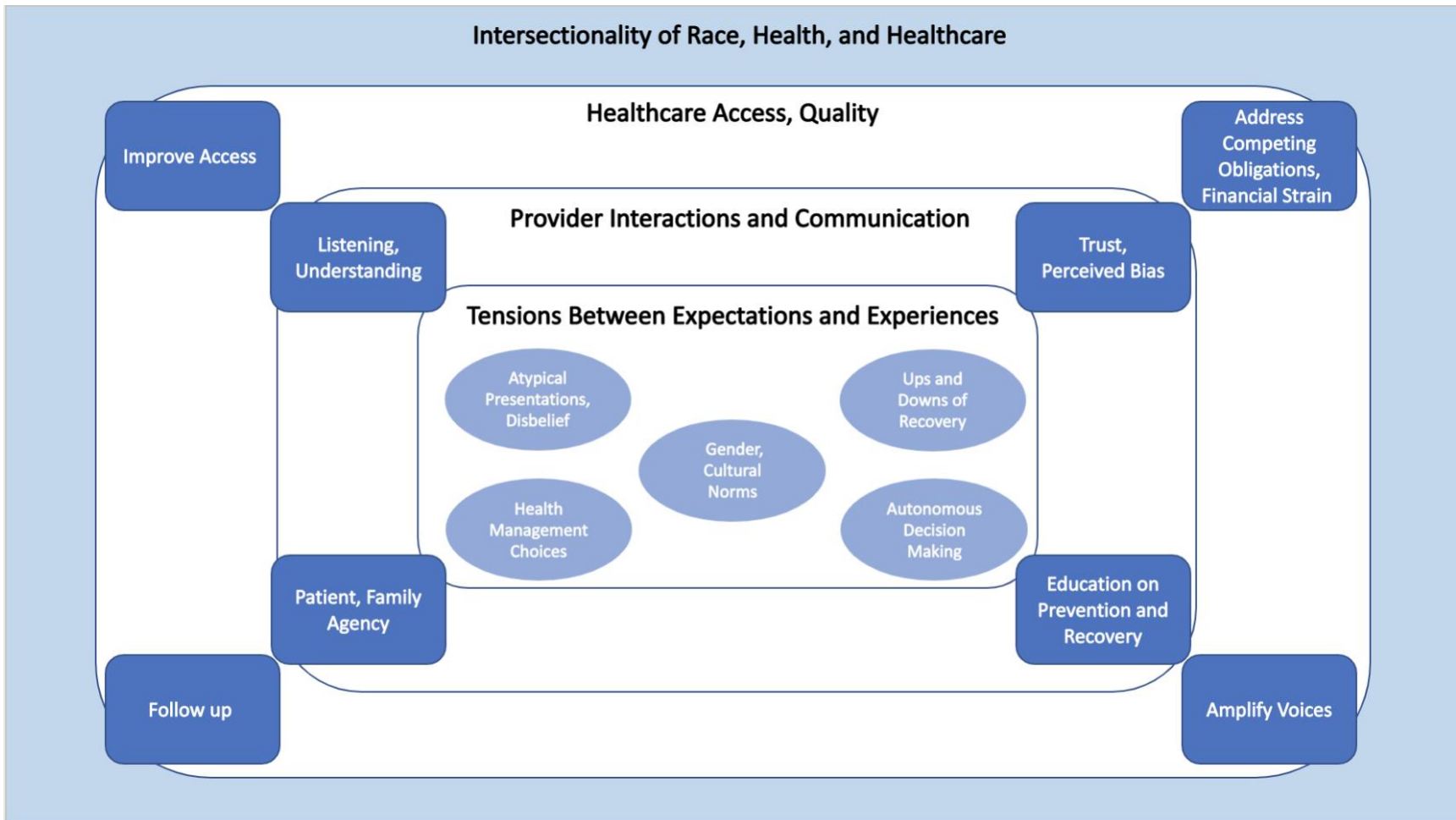
ID	Recruit source	Sex	Age, years	Education	Employment	SES	Household members	Emergency contacts	Health insurance	Medicaid	Perceived Stress	Perceived Racism	Discrimination
650	Past Study	Female	82	Masters	Retired	High income	1	2	Not employer sponsored	No	16/30	3/17	6/45
651	Pitt + Me Registry	Female	54	Bachelors	Student	Low income	2	4	Not employer sponsored	Yes	21/30	9/17	23/45
652	Pitt + Me Registry	Male	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>
654	Pitt + Me Registry	Female	68	Vocational	Retired	Low income	0	2	Not employer sponsored	Yes	<i>m.d.</i>	<i>m.d.</i>	<i>m.d.</i>
657	Pepper Registry	Female	63	High School	Disabled	Low income	0	4	Not employer sponsored	No	13/30	9/17	4/45
659	Pepper Registry	Female	74	Doctorate	Retired	<i>m.d.</i>	1	4	Not employer sponsored	Yes	20/30	3/17	22/45
660	Pepper Registry	Male	80	High School	Retired	Middle income	1	5+	Employer-sponsored	No	0/30	5/17	0/45
661	Pepper Registry	Female	80	Vocational	Retired	<i>m.d.</i>	1	1	Not employer sponsored	No	10/30	1/17	0/45
662	Pitt + Me Registry	Female	68	High School	Retired	Low income	0	2	Not employer sponsored	Yes	13/30	3/17	1/45
663	Pitt + Me Registry	Female	61	Associates	Retired	Low income	1	2	Not employer sponsored	Yes	11/30	1/17	35/45
665	Pitt + Me Registry	Female	54	Associates	Unemployed	Low income	3	5+	Not employer sponsored	Yes	18/30	10/17	26/45
669	Pitt + Me Registry	Female	66	Associates	Retired	Middle income	1	5+	Employer-sponsored	No	14/30	16/17	14/45
670	Pitt + Me Registry	Female	50	High School	Volunteer	<i>m.d.</i>	3	5+	Employer-sponsored	Yes	22/30	6/17	4/45

Note. *m.d.*, missing data. SES, Socioeconomic Status. PSS, 5 items, rated 1-5, higher scores=greater stress. Racism Scale, 17 items, higher scores=more instances. Discrimination Scale, 6 items, rated 0-5, higher scores=greater discrimination. Missing data indicated

### 3.2 Summary of Thematic Findings

Analyses culminated in four major themes: 1) *Intersectionality of Race, Health, and Healthcare*, 2) *Healthcare Access and Quality*, 3) *Provider Interactions and Communication*, and 4) *Tensions Between Expectations and Experiences* (Figure 1). The overarching theme of *Intersectionality of Race, Health, and Healthcare* characterized an awareness of elevated risk for stroke and stroke-related disability among people who are African American or Black, and thus the elevated need for good healthcare access and quality. *Healthcare Access and Quality*, characterized healthcare access and quality throughout the experience of stroke and recovery. *Provider Interactions and Communication* characterized participants' perspectives on how providers influence healthcare access and quality. *Tensions Between Expectations and Experiences* consider the “mismatches” between what they believed or were led to believe compared to what they actually experienced after their stroke.

It is helpful to consider these four major themes as concentric rectangles proceeding from participants' overall perspectives on healthcare quality and access to more specific perspectives, experiences, and decisions attributed to the specific health system and provider factors to even more specific perspectives, experiences, and decisions at the personal level. Perspectives on healthcare quality and access and system and provider factors were fairly consistent across participants, and they had similar environmental factors that shaped their experiences and decision making.



**Figure 1: Summary of Thematic Findings**

### 3.3 Major Theme 1: Intersectionality of Race, Health, and Healthcare

An overarching theme that emerged across the interviews was the intersectionality of race, health, and healthcare. Participants recognized that people who are African American or Black have a high risk for stroke and severe long-term stroke-related disability.

*“There is a higher percentage of African Americans that suffer from chronic diseases such as hypertension and diabetes. And, also, a higher percentage of stress and or PTSD due to being, you know, African Americans living in America...we are, of course, more prone to stress... and it can be very difficult to recover.”* (669)

High levels of stress was certainly a factor for several participants. For example.

*“I didn’t sleep because it was like - I was either at class or I had schoolwork, or I was at work. So I’m like sleep? What is sleep? I don’t even know what sleep is. 30 days later I was in the hospital.”* (651)

Participants also recognized the importance of good preventative care, as well as good urgent care during a stroke and good rehabilitation after stroke that addresses the needs of people who are African American

*“Well, since African Americans have a lot of significant health issues, it’s always important to eat properly, exercise, keep your weight at a reasonable amount...so knowing that there are just health issues that one must pay attention to. Plus, you know, going to get checkups, making sure you keep up with, you know, things like flu shots and shingle shots, and whatever else... So just keeping yourself aware of what’s going on in the health areas and much more so because you’re African American.”* (657)

Despite the awareness that people who are African American or Black are at higher risk for stroke and stroke-related disability, and the desire for good preventative care, each participant relayed several challenges with healthcare system access and quality, provider interactions and communication, and varied personal perspectives and experiences that complicated their experience of stroke and stroke recovery. These challenges are described in the following sections.

### **3.4 Major Theme 2: Healthcare Access and Quality**

Another theme that emerged across interviews is the value of good healthcare access and quality to minimize the burden of stroke and stroke recovery for African American people who experience stroke. Participants talked about how their experiences with healthcare prior to, during, and after their stroke influenced their experience of stroke. Perspectives on access spanned preventative, urgent, and specialty care across the continuum of recovery (pre-stroke and post-stroke acute, subacute, and chronic phases). Perspectives on quality focused on the importance of rehabilitation and follow-up care.

#### **3.4.1 Healthcare Access**

Participants described several challenges with limited access to healthcare services for a variety of reasons, exacerbating their health conditions and limiting the recovery process, demonstrating a need to **Improve Access**. One participant had her stroke while in prison and received little to no medical treatment. When asked, “Do you think you this contributed to the severity of your stroke?” she responded, “*Most certainly, most certainly... I received no medical*

attention in prison, so I went two and a half years before I received any medical attention” (659). This participant was not the only one to receive irregular healthcare prior to experiencing a stroke.

*“For a few years I didn't have any healthcare. I was sort of I guess destitute would be the word. So, I didn't have any healthcare for many years and that sort of exacerbated the- the conditions that I had, whether it was the diabetes or high blood pressure. So initially, before I was able to obtain healthcare, my healthcare was very irregular or spotty”.* (652)

Other participants discussed **Competing Obligations and Financial Constraints** that influenced access to healthcare. One participant elected to take public transportation to the emergency room in the middle of her stroke because she feared the cost of an ambulance:

*“My chest was hurting so bad, it felt like my ribs was broken. So, every time the bus hit a bump, I was in excruciating pain.”* (654)

Challenges with finances continued to impede healthcare access after initial medical treatment for stroke was concluded. In many cases, participants elected to not follow their provider’s advice for specialists to address post-stroke sequelae.

*“The insurance wouldn't cover it and they were trying to make me pay for it myself. And if I got the expert, they wanted 1500 dollars, and I'm like 'I'm not even working right now. So what am I going to do?' Disability turned me down twice.”* (651)

*“I have to address [the problem] myself. I'm on a fixed income and I have to pay for another provider.”* (654)

Even in the cases where participants did not face a financial barrier, many participants reported difficulty getting access to specialty providers. One participant searched for a psychologist for 5 months, and still had not found one at the time of the interview (650). One



participant attempted to utilize a stroke follow-up hotline provided by her doctor, but unfortunately the hotline was unresponsive leading to discouragement and withdrawal from future help seeking efforts:

*“Well, I tried the hotline so I could get a better understanding of the stroke... it was...one of the handouts that they gave me at the hospital, and they never called me back. I left two messages, and so I said, “Oh well, that's a joke...I'm on my own now.” So, I had to figure it out”. She found it... “very discouraging, but basically your health is really up to you.” (654)*

### 3.4.2 Healthcare Quality

Participants suggested several ways to improve the healthcare quality. One of the more specific suggestions was for providers to support routine **Follow Up** over the course of recovery, not just immediately after stroke.

*“And to do more follow up work. Like not, you know, ‘she's fine...she has insurance, she has a PCP, she's fine. If she needs us, she'll call us.’ Not necessarily like assign a social worker or anything like that, but just maybe do some- some follow up.” (669)*

*“Maybe bring the people in after they get a chance to settle down, after . . . you get an idea of what life looks like after. You can start noticing things, and you know, offer some services at that time.” (669)*

Participants also identified experiences that enhanced the quality of their stroke recovery.

*“My stay at [rehab facility] was very- I think- very rewarding. . . I think-after stroke that's the place they should go... Maybe sometimes you could think too much attention is not needed, but I was given that attention. Then I was allowed to have my family, even my*

*little puppy came to the hospital to see me... Yes... it was rewarding. You know, you didn't feel like you was sick or nothin', you just feel like it was away from home.” (650)*

Participants emphasized the need to **Amplify Voices**, or the perspectives and experiences of those who are African American to increase sensitivity towards their current perspectives and experiences and to incorporate their stories when seeking to improve healthcare quality. When asked, “What do you want to see come out of research that shares your experiences?” many participants underscored the importance of having a voice in their healthcare:

*“I really do appreciate you for doing the studies, because it does help get our information, our stories, and our experiences out there... so that our voices can be heard.” (670)*

### **3.5 Major Theme 3: Provider Interactions and Communication**

While discussing their experiences with healthcare, many participants shared perspectives about provider interactions and communications that affected their experience of healthcare and the healthcare choices that they made. Participants felt that providers should be responsible for educating themselves on the needs of each individual patient, to efficiently identify and address these patient needs, to treat each person respectfully, and to engage persons actively in healthcare decisions and treatments. Participants identified several provider characteristics that are important considerations when attempting to create healthier and stronger patient-provider relationships.

### 3.5.1 Listening, Understanding

Participants voiced the desire for providers to believe them when they share their histories and their pain. Providers who displayed this trait were successful in encouraging participants to continue rehabilitation efforts:

*“Because she believes me. When I tell her things, she believes me, and she encourages me to do well...you don’t get that from everybody.” (665)*

Several participants shared experiences when providers ignored their pain during healthcare visits prior to stroke that they felt influenced their willingness to seek treatment for stroke or engage rehabilitation:

*“That [was] one situation where [I] thought – there’s always this rumor about, you know, that Black folks don’t feel pain like [White] folks. And I’m like, that was very unprofessional... and I said I bet you if his daughter had to get that done, she’d get some pain meds.” (669)*

These negative experiences when participants felt “not heard” or misunderstood contributed to a desire for providers to show compassion, patience and tolerance recognizing that providers may not fully understand what patients are experiencing:

*“A person going into the medical field...would have to have compassion for the patients. They would have to have patience and tolerance, because sometimes it may seem like a person can do something, but you’re not wearing their shoes... You really don’t know their mental status as well as their physical status. So... you have to have compassion to be- to work in that field period.” (659)*

In addition to compassion, participants shared the need for providers to obtain the necessary education and training to understand the distinct life experiences of patients from various backgrounds:

*“Anyone going into the medical field, first of all, [should] make sure your professors... help you understand all people. Not just people like you. All people.”* (657)

*“I would like to see medical professionals in their training... specifically be taught... sensitivities to different groups. To women, to people that are, you know, immigrants, or first-generation people groups in this country, African Americans, people that have different abilities. That you have to be taught sensitivities. They’re not all exactly like you.”* (669)

### **3.5.2 Trust, Perceived Bias**

Given previous experiences when participants felt “unheard” or misunderstood, several participants admitted to difficulties with trusting healthcare systems and providers. As Participant 657 stated, *“What I’m going to say to you is and the study are very clear: African American women do not get good services at hospitals or with doctors.”* Participants challenged the belief that the negative perceptions of providers among African Americans are due to remote historical events like the Tuskegee experiment. Rather, participants frequently cited cumulative recent personal and family experiences that have eroded their trust:

*“We don’t necessarily trust the medical establishment as African Americans in this country, and it doesn’t have anything to do with the Tuskegee experiment. It has to do with experiences we’ve all had in that setting, including me. And there have been many times that I’ve looked and said: “You know what, you wouldn’t do that to your daughter” or “You*

*wouldn't want your wife treated like that. ” My husband, my mother, it's just - it's common... We [don't] talk about it a lot because we get accused of pulling the race card.” (669)*

These experiences emerged during preventative health services, urgent medical services at the time of stroke, and specialty services after stroke. Participant 665 described her experience with emergency personnel during her stroke, stating that they refused to listen when she and her family stated emphatically that her slurred speech was abnormal, and they took several minutes to understand the severity of the situation. The participant and her family perceived reluctance on the part of emergency personnel and felt that it was likely due to implicit bias.

Many participants shared similar experiences and stated that these experiences contributed to mistrust and delays in seeking treatment at each phase (preventative care, urgent care, and specialty care).

*“Lifestyle did not entail medical attention unless there was something major. When I got hit with an iron pipe and couldn't walk or something like that, or my elbow got busted open you know, something of that nature [I would go to the hospital]. But just as far as going to checkups, going for blood pressure, no that didn't happen.” (659)*

*“Many, many, many African Americans don't go to hospitals, don't go to doctors, because they are afraid of the whole process. They just don't trust.” (657)*

This trust may vary based on generation. As, participant 662 stated, *“Apparently, in that generation [referring to parents], anybody went to the hospital ended up dead...so you don't go to the doctor unless you're like almost dying.” (662)*

Mistrust appears to be prevalent, even when participants experienced what they perceived to be a good quality of care. Several participants voiced the need to remain cautious and vigilant. When asked if she had any positive experiences to share, one participant said, *“I made it out alive.*

*They didn't kill me, and I didn't kill myself.” (654). Another participant said, “It was very good. I was, I don't want to say I don't expect it, because I do want to be hopeful about that, but I am also watching. I am also very wary.” (669)*

The culmination of past interactions with providers led several participants to seek Black providers. When asked why she preferred African American providers, Participant 657 stated:

*“I felt more comfortable [with an African American provider] after my experience with that other person . . . who was like, you know, “Why are you here again? You're too old.” And I will never forget that. I should have had her written up because as you hear, there really was something wrong with me and I knew something was wrong. I just didn't know exactly what was wrong.” (657)*

Participants recommended that providers acknowledge and be sensitive to history and factors that contribute to mistrust if they are to effectively meet the needs of those who are African American:

*“It's gonna be important for the programming to change so that the young people coming out understand you have to build trust. They're [African Americans] not gonna just open their arms to you because things have happened in the past to African Americans. And so, their sense of trust, what their family has told them, what they might have experienced in the past, they don't trust.” (657)*

### **3.5.3 Patient, Family Agency**

Many of the experiences that shaped participants' trust in their providers also birthed a need to advocate for themselves and their families:

*“Educate yourself about being an advocate, having someone there taking notes.”*

(669)

*“You need the family, you need the village so to speak. Because mistakes happen...people don’t just die in hospital, but sometimes it’s because someone didn’t do what they needed to do correctly . . . Every time you have any issue, you’re fighting for your dignity, you’re fighting for the best care, you’re fighting to make sure that nobody makes any mistakes. You know, you’re up against it, and because you are not medically trained, you have to be your advocate, your own soldier, your own fighter for yourself.”*

(657)

*“So, we always, in my family, we always try to have an advocate for the patient. We’re very tight knit family, and we always have an advocate for the patient, always. If you’re in the hospital, you got a family member with you, period. So, everybody knows what’s going on, and so they see you’re loved and valued by someone else.”* (669).

Some participants voiced a desire to advocate for themselves, but feared humiliation or repercussions:

*“When we’re talking to doctors, and we don’t know what our rights are, what we have the right to know. Maybe I should know it already, so I didn’t want to humiliate myself or ask questions, I might have wanted to, or you know, I might have wanted to say there were some things I didn’t agree with, so I wanted to discuss it or maybe talk to somebody else about it.”* (670)

Some participants expressed a need to “do what the provider told them to do,” fulfilling social expectations to “obey.” As Participant 669 stated, “[We were] taught to be obedient to

*doctors, you know, from little kids.”* In many cases, participants talked about taking medications or undergoing medical procedures without a full understanding of what they were doing or why.

*“[I] took the medication that they prescribed to [me] for two months because [I] was afraid. [I] just didn’t know what was going on. [I] needed the understanding, you know, what was going on and how [I] didn’t want to make it worse by not taking the medicine.”* (654).

These insights highlight the need for open patient-provider communication and shared decision making. Recognizing the complex nature of patient-provider relationships in this context, providers must be thoughtful about sharing treatment options and discussing benefits and risks of these options to ensure understanding and to allow for informed decision making. In addition, providers must create room for patient and family agency to allow active contributions to health and recovery.

#### **3.5.4 Education on Prevention and Recovery**

Participants provided specific suggestions on how providers should approach patient education, stroke prevention, and recovery. For example, most, if not all, of the participants voiced concerns that they were unfamiliar with signs and symptoms of stroke. *“And that’s one of the- that’s one of the things I wish my doctor or some- somewhere along the line, I wish I had learned the other signs of a stroke . . . I didn’t know about slurred speech, the saggy face, none of that. I didn’t know that any one of those would mean get to the hospital immediately.”* (662)

Several participants reported that they had “atypical” presentations of stroke, with signs and symptoms not addressed in the traditional FAST acronym (Facial drooping, Arm weakness, Speech difficulties, and Time) (American Stroke Association).



*“FAST! I passed with flying colors. We went through it twice... I didn’t feel stroke-ish you know?” (669)*

*“When they talk about FAST, I never got the facial droop, I never slurred my words, none of that stuff, and I went back to bed” (651)*

*“I didn’t have any of the symptoms that I guess normally accompany strokes. I didn’t have any weakness on my facial features” (652)*

*“I was experiencing real bad ear aches. My scalp was so sore, I never experienced that before in my life.” (654)*

*“I didn’t have any, you know, speech impairment or anything of that nature. So, I wasn’t aware I even had it until I had the MRI.” (661)*

One participant believed that improved stroke education could influence those at an elevated risk to take preventative care more seriously.

*“We take our health for granted . . . we’re not really knowledgeable about healthcare, so we really don’t know what to expect, or to look for when we do. We need maybe a little bit more-a lot more, education, because sometimes... we take our health for granted.” (670)*

Other participants commented on the need for greater emphasis on preventative care and collaborative health management:

*“That kind of thing - I wish they would do more preventative health instead of waiting until you get sick and then want to treat you and give you medication and all that stuff. I think if they intervene before you have the problem it . . . would be easier to transition, you know . . . You know, black people, African Americans, we know there are certain health things that we deal with and I maybe I wish they would have insisted, you*

*know, pushed harder like 'hey you need to get your cholesterol check,' 'hey you need to get your mammogram,' 'get checked for, get your A1C checked,' because we know black people tend to get diabetes... Your cholesterol, that's a number you should know. Those things like that."* (651)

In addition, participants were seeking greater partnership with their primary care physicians in the management of health after stroke. Participants recognized the importance of collaborative health management to prevent a secondary stroke, and to support recovery.

*"Let's look at your nutrition ... to help your healing process. Let's look at some fitness options to help your healing process."* (669).

Overall, participants were seeking more information from their providers to recognize the signs and symptoms of stroke, even atypical presentations, as well as information to support collaborative health management prior to and after stroke.

### **3.6 Major Theme 4: Tensions Between Expectations and Experiences**

Participants identified several examples of "mismatches" between what they believed or were led to believe compared to what they actually experienced after their stroke.

#### **3.6.1 Atypical Presentation, Disbelief**

As stated earlier, many participants experienced a presentation of stroke that differed from what they were told to expect, and as such described difficulty believing that they were experiencing a stroke. For example, many participants were previously taught that the signs of

stroke were comprised of asymmetry in the Face, weakness in the Arm, altered Speech, and sudden change in a short Time. However, many participants did not experience these signs, were unaware they were having a stroke, and struggled to believe their diagnosis. Many participants reported that because of their “*disbelief*” they delayed seeking treatment until hours, days, or even months after stroke onset, in many cases adversely influencing their stroke recovery.

*“I didn’t realize I had had a stroke, to be honest with you.” (652)*

*“I’m always on Netflix watching on my tablet, and I just had a hard time with my left hand trying to touch the screen. And I thought maybe I was just still sleepy.” (657)*

*“I thought for maybe about one second that maybe it was a stroke, but I was like ‘No, it can’t be what it is,’ not wanting to alarm my family that night . . . [later] I still didn’t believe it, because it was not really a drastic change... I didn’t think it was bad enough where I couldn’t continue my day.” (651)*

*“I was surprised when they told me that I had it. When the doctor either told me that I had it I was surprised and it kind of shocked me...it scared me because I didn’t realize that I had something you know... I didn’t even know that I had it so it scared me knowing I could have had something that could have caused problems and was not aware of it.” (661)*

*“Stroke to me meant whole side paralysis. You can’t talk, you can’t walk... you’re arms freeze up. So, it never dawned on me that that’s what I had just experienced.” (662).*

*“I told my husband I worked too hard, it was really tough week my sinuses are messed up, I don’t feel good I probably just need- this is denial I’m not lying, it was. total denial. Total denial. I said I just need some good rest in my own bed.” (669).*

### 3.6.2 Gender and Cultural Norms

Two participants discussed how they believed that *societal gender norms* influenced whether and when they sought treatment:

*“[I wish] I didn’t wait as long as I did. I waited two days before I went to the hospital. A man thing, you know, ain’t nothing wrong with me.”* (660)

*“The women - we’ll discuss it and we’ll be like the first to go to the hospital or the emergency room. Where the guys... they’ll wait until they’re halfway dead.”* (665)

### 3.6.3 “Ups and Downs” of Stroke Recovery

Participants talked about the “ups and downs” that they experienced during recovery and the complex emotions that emerged over time.

*“It was just strange. Um, I’m telling my body what to do and it won’t do it. You know, those brain patterns have been made over my lifetime, like those neural connections... My brain’s telling my body it wants it to do this and I couldn’t do it. It was just the strangest thing.”* (651)

*“I would say that the process can be very cumbersome for individuals who know how to do things for such a long period of time, and then have that taken away from them.”* (652)

*“And I think I was starting to process it, and I just started crying . . . Once I start feeling frustrated about something, the depression comes on, and I get depressed because I can’t do this, and I could do it before I had the stroke.”* (651)

*“But I would not have been able to go to work. I didn’t even understand it at the time because I just wanted to get out of the hospital, and I wanted to pretend all of that didn’t happen. You know, it really didn’t hit me for a couple of days, maybe even a week, that I had a stroke. I went through depression. I went through a pretty good bout of depression after that.”* (669)

*“It was frightening. I was scared, and I had every reason to be. It was not a mini stroke, I was broken.”* (663)

However, not all changes participants experienced during recovery were negative. Some voiced positive changes that they valued.

*“I think I’m growing. I think I’ve grown a lot and with the help I’ve been getting in the last month or two has stopped me from feeling sorry for myself, because I can make some headway. I feel like I’m making headways, you know, that I’m getting a little bit stronger every day.”* (650)

*“So, I would want everyone to know that it’s a serious thing- it’s not something to play with. You know, and the aftermath of it is hard, but winnable, if you stick with it, if you try to overcome from it. But the patient has to be willing. The person, and anybody else that they go to, should be encouraging ...That would be really good, that would mean that this was a success, this research.”* (665)

Others expressed deep gratitude for the recovery that they had experienced.

*“I’m not the same as I was before, but I’m still alive. I’m walking and I can talk still. Very grateful. Grateful and humble.”* (663).

*“I’m alive, and I’m talking, and I can walk. I can move like I want to [cries]. I’m thankful. I’m just real thankful that I’m alive, and I can move around.”* (650)

*“I give all the credit to blessings from God, from being a child of God, and just having that drive for, you know, being saved from death, being saved from debilitation.”*

(669)

In addition, participants talked about changes in how they viewed themselves during the stroke recovery.

*“I didn’t feel right and this whole situation had made me feel, you know, really bad about myself. I didn’t like myself anymore . . . I am still not comfortable with I am, because I know I’m not supposed to be this way . . . This is just an awful feeling to know that you’re helpless.”* (650)

*“I always thought it happened to old people and they were permanently disabled. You know, the face droop, they need help bathing, eating, clothing. They just - you were debilitated.”*. (657)

*“I’m really going to need help now because I haven’t worked since I had my stroke. So I am a little anxious getting back into the work field, and what I am able to do.”* (651)

Participants talked about the importance of managing expectations – for both the person experiencing recovery and for those supporting this person.

*“I just want to be able to wash my hair again.”* (651)

*“I want to go back to work. I want to be the person that I was before.”* (650)

In some cases, communications around expectations were confusing and frustrating.

*“No, no, no. You promised me that I was gonna walk, so make me walk. You know, it was like my hopes were up and I’m telling my family . . . she said it so nonchalant. Off the cuff, you know. And it was just - I was just so mad.”* (665).

### 3.6.4 Health Management Choices and Implications

Several participants remarked that health management is an important factor in preventing stroke, recovering from stroke, and optimizing stroke outcomes.

*“I wish that the people, not just the medical field, it’s that the people who have these issues, would take them seriously, and be more mindful, and listen to their bodies. Because how I look at it, if I don’t tell you what’s wrong, you can’t fix it.” (659)*

*“I do know from past history to pay attention to what’s different in my body and get help for it.” (662)*

*“People have to be aware of the body and what it’s telling us and seek immediate attention.” (663)*

Participants also talked about the implications of their health management choices.

*“I had been given some meds to take and for some reason I didn’t want to take the pills. So, I think that helped the stroke to come. If I had taken the pills, maybe the stroke wouldn’t have come.” (650)*

In a similar vein, participants talked about health management strategies that were meaningful to them, such as eating healthily, exercising regularly, monitoring health changes, seeking medical attention for health issues, and adhering to prescribed treatments.

*“I have been, on a regular basis, attending doctor’s appointments . . . physical therapy, whatever I need to do. If a test needs to be taken, I follow through because I realize that my health is important.” (659)*

*“I think the most important part of the stroke is to take care of your blood pressure needs.” (650)*

*“[Cooking at home]. That just needs to be stressed a lot. But I do see a lot of people, they just rather take the pills.” (654)*

### **3.6.5 Autonomous Decision Making**

Several participants discussed a strong desire to maintain autonomy in their health management decision making.

*“I didn’t want to take the medication because I’m afraid of it, because the side effects.” (654)*

*“I didn’t want to take [the Botox injections] because I did some research on my own... and I found that some of the side effects could be long lasting... so I told him that I didn’t want to take shots anymore. In fact, I felt that at that time that the shots were making me worse. Making me less able to maneuver for myself.” (650)*

Many participants preferred alternative treatment options that were not offered by their providers. Participant 669 had specialized training as a fitness instructor and chose to use her expertise to monitor and promote her recovery without the support of rehabilitation professionals.

*“Well, being a fitness instructor, I wrote my own Program... I didn't necessarily feel like I needed them to do it [the rehab] . . . You don’t necessarily have to force occupational or physical therapy on a patient if they don’t want it.” (669)*

Each of these perspectives on personal health management point to the need for individualized assessments and collaborative health management plans during preventative care, urgent care, and specialty follow-up care.



## 4.0 Discussion

The intent of this study was to explore the perspectives and experiences of people who are African American or Black and have sustained a stroke, to add to our understanding and to explore the impact that these perspectives and experiences have had on stroke and stroke recovery. The findings provide rich information to inform strategies to improve healthcare access and quality, provider interactions and communication, and the individual experience of stroke and stroke recovery. We will discuss our findings using the Institute of Medicine's six aims for the healthcare system: 1) *Safe*, 2) *Effective*, 3) *Patient-Centered*, 4) *Timely*, 5) *Efficient*, and 6) *Equitable* (Institute of Medicine, 2001).

*Safe* healthcare is defined by “avoiding harm to patients from the care that is intended to help them.” Several of the participants described several instances of “harm.” Participants felt “unheard,” “misunderstood,” and hesitant to ask questions about their health and provider recommended treatments. In several cases, this led to avoidance of preventative care, delays in seeking urgent care, and declinations of follow-up or specialty care. Participants cited a lack of understanding or fear of unsafe side effects as leading reasons that they elected to decline provider recommended medications, rehabilitation, and additional treatment options. Fear for physical and emotional safety was embedded in prior personal or family experiences with the healthcare system or providers, pointing to the need to establish rapport and trust with people at risk for or experiencing stroke if healthcare systems and providers seek to provide a safe treatment environment.

*Effective* is defined by “providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse

and misuse, respectively).” Evidence-based clinical practice guidelines recommend that people who are experiencing stroke signs and symptoms should be seen by a stroke neurologist as soon as possible to assess the need for acute medical intervention (American Stroke Association). However, several participants identified a host of reasons for delays upon onset, including failure to recognize the signs and symptoms of stroke (in some cases due to atypical presentation), personal disbelief, mistrust of the healthcare system, and not being taken seriously by pre-hospital providers. These barriers prohibit the delivery of effective acute stroke management.

Evidence-based clinical practice guidelines also recommend that after evaluation by a stroke neurologist, people who experience a stroke should be evaluated by a well-organized interprofessional team (that includes the patient and family) to promote return to activity and mobility as soon as possible, and to assesses communication, basic and instrumental activities of daily living, and residual neurological impairments (Powers et al., 2019). Such an approach leads to more effective healthcare utilization and better functional outcomes over the long-term. Interviews suggest that participants had varied experiences with respect to exposure to and follow-through with rehabilitation services and providers. These variations were in part due to personal factors (e.g., availability of insurance, trust of the healthcare system), but may also be due to variations in system and provider implementation of clinical practice guidelines. However, data from the current study are insufficient to support or refute this point, and further investigation is warranted.

*Patient-centered* healthcare is defined by “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” Each participant shared concerns about provider-patient interactions and communication that were characterized by a lack of respect or responsiveness to patients’

preferences, needs and values. Participants discussed the desire to be listened to and understood and to establish trust and minimize biases. They suggested that providers receive education aimed at increasing sensitivity to the lived experiences, personal factors, and environment factors influencing people who are African American and who have experienced a stroke.

In addition, participants emphasized the need for collaborative health management where practitioners provide multiple treatment options and involve patients actively in shared decision making. This could be supported by creating room for patients and families to ask questions and recognizing that in doing so patients and families may need encouragement to do so. Healthcare systems could develop ways for patients to give feedback on their interactions with providers without fear of repercussions. Anonymous surveys that explore perceptions of bias, microaggressions, or disrespect may be necessary to enhance a culture of trust among patients and their providers. Participants also suggested having regular follow-up appointments, not just immediately after their stroke, but throughout the recovery process as their physical, cognitive, and emotional states change drastically. Tracking these changes over time may lead to new insights when delivering services to this population.

*Timely* healthcare is defined by “reducing waits and sometimes harmful delays for both those who receive and those who give care.” Participants identified several barriers to timely healthcare after stroke. Many did not recognize their signs and symptoms in a timely fashion, either because they did not know the warning signs, or they experienced an “atypical presentation” meaning that they had a headache or blurred vision in place of FAST symptoms. A published review of several studies suggests that there are differences in recognition of stroke signs and symptoms among people who are African American or Black relative to other populations (Sharrief et al., 2016). Nonetheless, given the high risk and high incidence of stroke among people

who are African American or Black, there is a need for focused community-based education programs on stroke prevention and recognition that are accessible and tailored to the needs of these communities. Thus, an approach that is tailored to the majority of the population but neglect the distinct needs of a critical segment of the population may miss the mark.

Participants also expressed hesitation in seeking healthcare once they identified that they were experiencing a stroke because of previous negative experiences with the healthcare system or providers that contributed to mistrust. Community education programs must be responsive to the lived experiences of the community and confront the issues of trust and incorporate patient and family agency if they are to be successful. Our findings also suggest that attention must be paid to gender and cultural norms as well as financial challenges and barriers.

*Efficient* healthcare is defined as “avoiding waste, including waste of equipment, supplies, ideas, and energy.” Several participants received treatments they perceived as unnecessary including medications, physical and occupational therapy, and physical aids such as walkers. In one case, a participant expressed frustration that she had specialized training to design her own physical exercise program and did not feel that this expertise was acknowledge by her provider. Encouraging more collaborative health management and allowing patients to have a more active role in shared decision making could allow for more Black people to follow treatment plans.

Finally, high-quality healthcare should be *equitable*, defined by “providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.” All participants acknowledged that intersections among race, health, and healthcare in the United States are complex. Participants started by acknowledging their increased risk for stroke and stroke-related disability, as well as their need for good healthcare

access and quality. However, this awareness is confounded by previous experiences that have eroded trust. Many participants have found ways to improve their access to and quality of healthcare through education and patient and family advocacy. Many of the same participants commented on the need to rely on themselves and their families to manage their own personal health. These strategies, while commendable, are unnecessary in an equitable healthcare system. Rather, equitable access and quality should ensure that all persons receive the right care, at the right time, in the right response to their individual needs. Participant interviews point to the fact that additional work is needed to achieve this goal of equitable healthcare.

Clearly, participant interviews revealed several areas in need of improvement if we are to achieve quality healthcare for people who are African American or Black and experiencing a stroke. Participants provided suggestions for healthcare system access and quality, provider interactions and communication, and personal health management to improve stroke outcomes. Their perspectives, experiences, and suggestions provide a clear roadmap for how we can improve healthcare to prevent stroke when possible and treat and management stroke consequences when necessary. Nonetheless, our study represents a small sample in one city with access to a large academic health system. Findings may not generalize to other regions without access to these same resources. Furthermore, cultural norms and expectations vary in different regions of the United States and may not be fully represented within this sample. For this study, we chose to focus on the perspectives and experiences of people who are African American or Black, but studies demonstrate that inequities in stroke outcomes exist in several minority populations, including those from Hispanic and Latinx backgrounds, those from low-income areas, and those who are marginalized due to pre-existing disability. Future studies should explore the perspectives and

experiences of these people groups to ensure representation in efforts to improve healthcare access and quality across the nation.

## 5.0 Conclusion

Semi-structured interviews of people who are African American or Black and had experienced a stroke revealed four major themes: 1) *Intersectionality of Race, Health, and Healthcare*, 2) *Healthcare Access, Quality*, 3) *Provider Interactions and Communication*, and 4) *Tensions Between Expectations and Experiences*. Major themes and sub-themes draw awareness to and educate healthcare professionals on the nuanced experiences of African American people after stroke; and point to focused strategies for provider training, community education, and healthcare and rehabilitation delivery to be more responsive to the needs of this population.

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