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EXPLORING THE ROLE OF CULTURE AND RACE IN STROKE REHABILITATION DISPARITIES

by

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Submitted in Partial Fulfillment of the Requirements

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DEDICATION

This is dedicated to all the Sistahs who came on a boat against their will across the Atlantic Ocean enslaved physically, but not mentally because they had a glimmer of hope that trouble does not last always and if it did, Sistahs knew how to persevere. This is also dedicated to the Sistahs who came before me in higher education, obtained the Ph.D., became academicians, and decided to become a part of the professoriate. Sistahs, I have enjoyed watching you and commend you for making it across home plate. Although I was invited to play the game, I realized that when I came up to bat, the rules changed because of the color of my skin, and therefore, I have decided that I do not want to play in the game.

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④ ACKNOWLEDGEMENTS

I would like to thank my husband, Kenneth C. Greene. I now understand what a love language is because of this doctoral process. I will always be Mrs. Greene first and foremost. I love you forever, unconditionally. Thank you Stacy L. Fritz, Ph.D., MSPT for seeing me through the process. I can see clearly now that the process is over. I am looking forward to brighter days ahead. J. Larry Durstine, Ph.D., I appreciate your continuous support of me as I chose a nontraditional path in Exercise Science research. Daniela B. Friedman, MSc., Ph.D., I appreciate your expertise in health communication and qualitative methodology. Roger Newman-Norlund, Ph.D., I appreciate your asking the tough questions to make me think beyond what I see as important. It proves that you are listening and learning. Michelle Bryan, Ph.D., as a critical race theorist, whom I view as a critical race scholar, I am appreciative of the fact that you understand race matters, because you know how race operates and have experienced racism in the academy, and as a scholar, you know how to articulate race and racism, especially as an expert in qualitative methodology. I hope one day to have that swagger in my talk. As members of my dissertation committee, I express my gratitude to all of you for your assistance during the dissertation phase. Last,

Dear Momma,

I'm so glad you prayed for me, had me on your mind, you said a little prayer for me. I'm so glad you prayed for me. I never would have made it. That praying is a powerful thing. Thank you.

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ABSTRACT

A study found that racial differences exist in stroke rehabilitation care and outcomes between African Americans (AAs) and Caucasian Americans (CAs). In addition to health status, the rehabilitation care of AAs with stroke (AAwS) may be influenced by cultural and or racial similarities or differences that exist between themselves and their physical therapists (PTs). Distorted perceptions of culture and race in the patient-PT relationship may contribute to disparities in stroke rehabilitation care and outcomes for AAwS. Current stroke rehabilitation literature lacks qualitative research that examines racialized differences in treatment. The purpose of this qualitative exploratory research study was to investigate the perspectives of: (1) AAwS regarding the ways in which culture and race may have influenced their physical therapy experiences during inpatient rehabilitation, and (2) PTs regarding how culture, race, and health status (latter two evidenced in literature) contribute to the disparities in rehabilitation care and outcomes for persons with stroke. Semistructured individual and paired interviews were conducted with a purposeful criterion sample of five AAwS. Semistructured focus group interviews were conducted with a purposeful criterion sample of PTs. Interviews were digitally recorded, transcribed verbatim, and content analyzed. Data analysis revealed six themes for AAwS: (1) self-acknowledgement, (2) shift in barriers to optimal health, (3) health cultured inferiority or subordination, (4) health outcome investment with a subtheme, culturally-relevant and functional activities, (5) issues of trust, and (6) race role interaction. Six themes emerged for PTs: (1) justice and equality, (2) family capacity,

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(3) patient-PT relationship, (4) health outcome investment, with a subtheme of physical therapy intensity, (5) systematic healthcare limitations, and (6) patient social health attributes. The diversity of these themes demonstrates the complexities involved in providing equitable care related to culture, race, and health status. Also, culture and race of the patient and PT are characteristics that factor into the patient-PT relationship in physical therapy practice. Future qualitative studies should interview and observe patient-PT dyads to investigate how physical therapy practice and the patient-PT relationship can accommodate the factors of culture, race, and health status to eliminate disparities in stroke rehabilitation care and outcomes between AAs and CAs.

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LIST OF ABBREVIATIONS

AA……………………………………………………………...……..…African American

AAs……………………………………………………………….African Americans

AAwS…………………………………………….....……African Americans with Stroke

AME……………………………………………………....African Methodist Episcopal

APTA……………………………………….....American Physical Therapy Association

BIT………………………………….……………………..Black Identity Theory

CA……………………………………….....…………………..Caucasian American

CAs………………………………………………………………..Caucasian Americans

CMs…....………………………………………………………………Case Managers

CRT…………………………….……………………………………Critical Race Theory

ECG………………………………………………………………..…Electrocardiogram

ED………………………………………………………………Emergency Department

FDA…………………………………………………….....Food and Drug Administration

FG…………………………………………………………………………….Focus Group

FGs……………………………………………………………..……………Focus Groups

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FIM……………………………………………………….Functional Independence Measure

ICR…………………………………………………………………Intercoder Reliability

IRB………………………..……………………………………Institutional Review Board

IRFs…………………………………………………..….Inpatient Rehabilitation Facilities

LOS……...………………………………………………………………….Length of Stay

NINDS…………………………....National Institute of Neurological Diseases and Stroke

PA……………………………………………………….………..….…Primary Author

PI……………………………………………………………………Principal Investigator

PT……………………………………………………………………..…Physical Therapist

PTs………………………………………,………………………Physical Therapists

RA………………………………………………………………………Research Assistant

RIT………………………………………………………………..…Racial Identity Theory

RQ………………………………………………………………………Research Question

RQs……………………………………………………………….……Research Questions

SIT…………………………………………….…………….…Symbolic Interactionism Theory

SLT……………………………………...……………….....…Sociocultural Learning Theory

SWs………………………………………………………………......….Social Workers

tPA……………………………………………………………..…Tissue Plasminogen Activator

USC …………………………………………………...…….University of South Carolina

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CHAPTER 1

INTRODUCTION

An estimated 7 million persons are living with stroke in the United States[1] and AAs, many of whom live in the Stroke Belt located in the southeastern region[2] are twice as likely to have a first-ever stroke compared to CAs.[3,4] South Carolina ranks fifth in stroke mortality rate in the nation and AAs are 61% more likely to die from stroke than CAs in South Carolina.[5] African Americans with stroke (AAwS) report inadequate amounts of exercise,[6] higher rates of disability poststroke,[7] and are more likely to have a second stroke compared to CAs.[8-11] Therefore, inpatient stroke rehabilitation programs need to address these stroke health disparities. All persons with stroke are different based on lesion site and type of impairments; thus, there are not any standardized applications of physical therapy interventions.[12] Hence, extensive research has been conducted in an effort to explain the "black box" of stroke rehabilitation.[12-16]

The black box is a metaphor (Gerben DeJong, Ph.D., FACRM, Senior Fellow & Director, Center for Post-acute Innovation & Research, National Rehabilitation Hospital & MedStar Health Research Institute, Email Conversation, February 24, 2012) used to describe the process of critically analyzing which components of rehabilitation care (length of stay (LOS),[17,18] time intensity,[18-20] or the type of activities practiced and treatment interventions provided to achieve those activities[18-21]) contribute to stroke rehabilitation effectiveness. Stroke rehabilitation effectiveness depends on

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patient characteristics and care and outcome processes; however, culture and race are not acknowledged as patient characteristics (as defined in the rehabilitation outcome literature)[15] that contribute to factors of rehabilitation effectiveness. Instead, patient characteristics are defined as prestroke history, social support, cognitive functioning, and severity of illness.[15] Thus, although the black box of rehabilitation acknowledges individualized care based on stroke impairment, it fails to consider how the perceptions of race and culture and the role culturally-relevant therapy may play in social interactions between AAwS and physical therapists (PTs).

1.1 TERMS AND DEFINITIONS

For the purposes of this study, *time intensity* is the number of minutes per day in functional activities or treatment interventions within a specific functional activity.[20] *Race* is "ancestry and selected physical characteristics, such as skin color, hair texture and eye shape."[22(p27)] Moreover, race is a "pseudo-biological concept"[23(p1208)] that is used to validate the disparate treatment of individuals based on visible physical characteristics. *Culture* is

> …the sum of intergenerationally transmitted and cross-culturally acquired lifestyle ways, behavior patterns, and products of a people that include their language, music, arts and artifacts, beliefs, interpersonal styles, values, habits, history, eating preferences, customs, and social rules. Furthermore, culture can be characterized by people who share a common geographic place, common experiences, and a specific time in history.[24(p1)]

Culture as it specifically pertains to *health behavior* is the distinctive shared values, beliefs, and practices that are directly or indirectly associated with that behavior, and or influences acceptance and adoption of the health education message.[25] *Racial* as an adjective is relating or pertaining to the characteristic of race.[26] *Background* is an individual's training or experience and events leading up to something.[26] Therefore,

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racial background is the experiences or events that are related to a person's race and similarly, *cultural background* is the experiences or events that are related to a person's culture.

1.2 RESEARCH PROBLEM

Distorted perceptions of race and culture and the lack of knowing and understanding cultural habits may contribute to the disparities in stroke rehabilitation care and outcomes for AAwS. Research indicated that adherence to health behaviors will decrease the risk of second stroke in AAs.[8,10] Physical therapy interventions during inpatient rehabilitation should be culturally relevant, which may possibly contribute to health behaviors that could prevent the occurrence of second stroke in AAs. Racial differences and the lack of knowing and understanding cultural habits of AAs by PTs however, may contribute to physical therapy interventions that are not culturally relevant. Therefore, future studies should assess the potential role that racial and or cultural differences between AAwS and the PT may have on the experiences of AAwS during inpatient rehabilitation. In addition, Horn et al suggested that future studies investigate the ways in which a person's race or health is associated with the choice of activities and treatment interventions within activities and clinical reasoning processes of therapy providers.[20]

Quantitative studies have found that racial differences exist in stroke rehabilitation care and outcomes between AAs and CAs.[20,21] The rehabilitation care experiences of AAwS, in particular, may be influenced by racial and or cultural similarities or differences that exist between themselves and their PTs. The current stroke rehabilitation literature however, lacks qualitative research that explores racialized differences in

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treatment. Racial identity and cultural mistrust have a critical influence on successful rehabilitation and may contribute to decreased success in rehabilitation outcomes experienced by AAwS.[27,28] If persons are accepted to a rehabilitation facility, positive health behavior change is linked to provider trust and communication, and participatory decision-making,[29,30] all of which are part of the patient experience that occurs during rehabilitation care. The possibilities for positive health behavior change for AAwS may be compromised when PTs lack an understanding of specific cultural variables that are present in the lives of their AA patients, which may bear significantly on their capacity to maintain recommended treatment intervention strategies. Hence, a qualitative investigation was needed to better understand how: (1) culture, race, health status, and cultural and racial background, and (2) cultural understanding and sensitivity towards AAs as perceived by AAwS and PTs may be implicated in stroke rehabilitation care and outcomes and thus, possibly contribute to the stroke health disparities (inadequate amounts of exercise, higher rates of disability, and stroke reoccurrence) that negatively impact AAs.

1.3 STUDY AIMS

The purpose of this study was to explore the perspectives of: (1) AAwS regarding the ways in which culture and race may have influenced their experiences during inpatient rehabilitation, and (2) PTs regarding how culture, race, and health status (the latter two as evidenced in the literature)[20] contribute to the disparities in rehabilitation care and outcomes between AAs and CAs with stroke. The proposed research questions (RQs) for this study were:

RQ1: What are the perceptions of AAwS regarding the ways in which culture and race may have played a role in their inpatient rehabilitation experiences?

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RQ2: What are the perceptions of PTs about how culture, race, and health status of persons with stroke may be associated with the type of activities, type of treatment interventions within activities chosen, and time intensity of each as evidenced in the rehabilitation literature?[20]

The goal of this research study was to use qualitative methodology (interviewing and content analysis) to explore inpatient stroke rehabilitation care and outcome disparities from the perspectives of AAwS and PTs. These perspectives from AAwS and PTs can contribute to the evidence-based practice of neurorehabilitation and health promotion by providing commentary on how PTs should acknowledge race and consider its intersection with culture when developing what should be culturally-relevant interventions in order to decrease the risk of second stroke among AAs. This dissertation research was significant because it was imperative to better understand the ways in which the intersection of culture, race, health, and other contextual factors that emerged (e.g. education level and socioeconomic status) influenced inpatient stroke rehabilitation care and outcomes.

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CHAPTER 2

REVIEW OF THE LITERATURE

A cerebrovascular accident (CVA) or stroke occurs when blood flow in the brain is interrupted due to a blocked (ischemic) or ruptured (hemorrhage) vessel and the deprivation of oxygen leads to nerve cell damage or death.[2,31] As a result of stroke, individuals have impairments in cognition, mental status, vision, sensation, strength, balance, and affect resulting in decreased independence in daily living skills.[32] Stroke prevalence is estimated at 7 million persons greater than or equal to 20 years of age in the United States.[1] Nationally, 4.5% of men and 4.4 % of women who are non-Hispanic AAs greater than or equal to 20 years of age have had a stroke compared to 2.4 % of CA men and 3.3 % of CA women.[1] In a national cohort study, weighted in favor of southeastern states and AAs, stroke symptoms were more likely among AAs compared to CAs.[33] These stroke symptoms were hemibody numbness and weakness, periodic loss of vision in one or both eyes, no pain associated with weakness or vision loss, inability to speak clearly, and inability to understand speech.[33] In South Carolina, the stroke rate has shown a small increase for AAs (.41% , .41%, and .42%) and CAs (.38%, .39%, and .40%), but was comparable for both groups from 2008 to 2010 respectively[34,35] (Chris Finney, MIS, Program Manager, Office of Research & Statistics, S.C. Budget and Control Board, Email Conversation, March 28, 2012).

2.1 STROKE HEALTH DISPARITIES

A health disparity as defined by Healthy People 2020 is:

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> …a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.[36(p1of2)]

Among dictionary definitions, disparity is described as an inequality, thereby unequal.[26,37] But disparity in health care is an all encompassing term to include: (1) differences in environment, (2) access to, utilization, and quality of health care, (3) health status, and (4) the health outcome of interest.[38] The term represents a state of being or condition, but it is not clearly delineated how the disparity comes into being in health care. The critical component is that treatment or outcome is not justified by the primary need of the individual.[39] Relevant to this study, health disparities may result because of three factors that have been identified in patient-physician practice, which are prejudice, clinical uncertainty, and stereotyping,[39-41] and another factor related to the patient, payor source or insurance status.

Disparities occur in stroke care from diagnosis to rehabilitation. Upon arrival to the emergency department (ED), 58% of persons with stroke were not seen by an ED physician within 10 minutes, as recommended by the National Institute of Neurological Diseases and Stroke (NINDS).[42] Moreover, AAs had a longer wait time than CAs.[42] African Americans were less likely to have diagnostic imaging within 25 minutes[42,43] and more likely not to receive tissue plasminogen activator (tPA), the only Food and Drug Administration (FDA)-approved treatment for stroke which causes brain reperfusion,[44-49] especially if the attending physician was not a neurologist at an urban academic medical center.[43]

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African Americans have a greater first time incidence of ischemic and hemorrhagic strokes, twice the rate of CAs[3,4,50-54] and particularly at younger ages (20-54) compared to CAs.[4,50,52,55] Specifically, AAs are more likely to have ischemic strokes due to intracranial atherosclerotic disease, such as lacunar infarcts.[1,4,56-59] Caucasian Americans are more likely to have hemorrhagic strokes, extracranial carotid stenosis, and atherothromboembolic events and or cardioembolic events due to atrial fibrillation.[1,56-59] These disparities in stroke subtype however, may be a result of clinical practice. These statistics have been challenged due to changes in diagnostic evaluation. When using diffusion-weighted magnetic resonance imaging as a method of full diagnostic evaluation, similar proportions of ischemic and cardioembolic strokes exist between AAs and CAs.[60] African Americans with stroke are less likely to receive comprehensive noninvasive stroke testing[61] including rehabilitation evaluations,[62] and cardiac monitoring.[61] Furthermore, when confirmed by electrocardiogram (ECG), AAs were less likely to be aware of the fact that they had atrial fibrillation or the medication intervention for it when compared to CAs.[63] Hence, these findings support the disparity in health care: AAs are not often given equitable diagnostic opportunities that would prove beneficial for treatment and their health outcomes,[64,65] particularly in diagnosing first-ever strokes.[4] Moreover, these studies and the leading organizations providing the statistics did not provide psychosocial reasons related to culture, race, or the cultural and racial background of the patient and provider as possible causes of the disparities.

Data demonstrate that for persons discharged from South Carolina hospitals with a primary diagnosis of stroke, CAs have significantly higher extracranial strokes related to embolism, thrombosis, and or arterial narrowing and obstruction compared to AAs

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(2010: 85.49% versus 14.51%, respectively and 2011: 85.20% and 14.80%, respectively) (Chris Finney, MIS, Program Manager, Office of Research & Statistics, S.C. Budget and Control Board, Email Conversation, May 29, 2012). In addition, there is a higher percentage of CAs with discharge diagnoses of hemorrhagic and ischemic strokes compared to AAs. In 2010, 61.13% of CAs had a discharge diagnosis of hemorrhagic stroke versus 38.87% for AAs and in 2011, 62.22% versus 38.78%, respectively. In 2010, 64.48% of CAs had a discharge diagnosis of ischemic strokes versus 35.52% for AAs and in 2011, 64.74% versus 35.26%, respectively. Compared to published reports,[1,56-59] South Carolina statistics similarly demonstrate that CAs have more discharge diagnoses of extracranial strokes and hemorrhagic strokes compared to AAs; however, unlike those reports, CAs also have more discharge diagnoses of ischemic strokes compared to AAs. These statistics are important to note for rehabilitation and prognosis, because overall, persons with hemorrhagic stroke are more acutely ill, have a higher mortality rate, and a poorer prognosis in terms of functional outcomes related to stroke severity and impairment compared to persons with ischemic stroke.[31,66,67-69]

Following acute stroke, persons are assessed for rehabilitation and placed based on clinical need, level of impairment, and resources (including financial and social support).[15] Persons with stroke are the largest group of postacute rehabilitation services consumers[12,13] and 17% of all inpatient rehabilitation admissions.[13] When accounting for patient differences, starting early and having aggressive rehabilitation is better.[12,13] Stroke rehabilitation encompasses regularly planned therapeutic interventions involving flexibility, strength, balance and aerobic training, and learning and practicing daily living skills from occupational, speech, and physical therapists. Additional services are

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provided during inpatient rehabilitation that include psychology, social work, therapeutic recreation, chaplaincy, vocational rehabilitation, and rehabilitation engineering.[12] Inpatient rehabilitation can occur at a free standing facility or a hospital-based unit.[12] The rate for all stroke discharges from nine inpatient rehabilitation facilities (IRFs) in South Carolina was consistently higher for AAs compared to CAs from 2008 to 2010 (7.93% versus 5.73%; 7.97% versus 5.67%; 6.94% versus 5.45%, respectively). This trend continues in 2011 for AAs (6.94%) compared to CAs (5.88%) (Chris Finney, Email Conversation, March 28, 2012); however, it is unknown which components of stroke care impact inpatient rehabilitation outcomes for AAs who are disproportionately and negatively affected by stroke.

In a prospective observational cohort study of six IRFs across the United States, admission rates and therapies varied by stroke severity and race.[20] *Therapy activities* were functional activities (bed mobility, gait (walk) training, transfers and community mobility), whereas *therapy interventions within activities* were methods or modalities required to perform activities (strengthening, range of motion, and body weight supported walking).[20] For persons with moderate stroke, CAs had more minutes/day in transfers (significant, $p<.017$), sit to stand training (significant, $p<.009$), and community mobility (significant, $p<.007$) activities.[20] African Americans had more minutes/day in wheelchair mobility that was significant ($p<.020$).[20] For physical therapy interventions within activities, significant racial differences were seen for CAs having higher values in minutes/day for community mobility motor learning ($p<.001$), gait family caregiver education ($p<.001$), and transfers perceptual training ($p<.001$), whereas AAs had higher values in minutes/day for motor control in sitting and prefunctional activities (significant,

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$p<.030$ and $p<.024$, respectfully).[20]

For patients with severe stroke, CAs had two more days in inpatient rehabilitation compared to AAs. For activities, CAs had more minutes/day in transfer training, whereas AAs had more minutes/day in wheelchair mobility (both significant, $p<.001$).[20] African Americans had more therapy patient education and formal assessment time (significant, $p<.021$ and $p<.025$, respectively).[20] Specifically, for physical therapy interventions within activities, significant racial differences were seen for CAs having higher values in minutes/day for community mobility balance training ($p<.009$), gait family caregiver education ($p<.020$), and transfers perceptual training ($p<.001$), whereas, AAs had higher values in minutes/day for prefunction motor control ($p<.001$), and wheelchair patient education ($p<.016$).

Overall, CAs with moderate and severe stroke received more minutes/day in physical therapy activities and interventions than AAs; however, AAs had significant ($p<.001$, moderate stroke and $p<.031$, severe stroke) longer median session duration (minutes/session) of non-physical therapy engagement. *Median session duration* "represents a specific predetermined time interval that each facility provides to their patients as a policy (Susan D. Horn, Ph.D., Senior Scientist, Institute for Clinical Outcomes Research & Vice President, Research, International Severity Information Systems, Email Conversation, July 3, 2012). Per Dr Horn, "the clock was ticking with no activities, or there were rest periods between activities, or that the actual treatment time was not always provided according to the predetermined session time." Perhaps though, these findings suggest that there was time during the sessions that AAwS were not engaged in therapy-related activities or interventions within activities. Caucasian

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Americans were engaged in therapy-related interventions and or activities during the majority of the sessions, thus explaining the finding that CAs had higher minutes/day.

African Americans were discharged to inpatient rehabilitation sooner compared to CAs and this could be attributed to the fact that acute care hospitals discharge self-pay and Medicaid patients sooner because of lower reimbursement for hospital care.[20] The IRFs' admission health status for persons with moderate stroke were similar between AAs and CAs; however, for persons with severe stroke, CAs were sicker compared to AAs. Persons with moderate stroke tend to be younger AA females, hypertensive, obese (body mass index greater than or equal to 30), less independent or ambulatory prior to stroke, and more likely to be on Medicaid compared to CAs.[20] Even though the health status for CAs with moderate stroke was similar to AAs, CAs received more stroke care in terms of nontherapy ancillary services and minutes/day in therapy activities and interventions within activities. The finding of more stroke care in terms of nontherapy ancillary services and minutes/day in therapy activities and interventions within activities was the same for CAs with severe stroke compared to AAs with severe stroke, despite the fact that CAs were sicker compared to AAs. These results indicated that there is a disparity in stroke rehabilitation care, including nontherapy ancillary and therapy services.

From the same dataset, CAs and AAs were given a greater number of sessions of interventions within activities that were both associated with higher and lower discharge motor Functional Independent Measure (FIM) scores.[19] After controlling for patient characteristics and therapy variables, (interventions within activities, and the time devoted to activities and interventions), no racial differences existed in discharge motor

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FIM scores.[19] If equitable therapy is given for clinical need in type and time in activities and interventions, then functional outcomes should be improved and the same for AAs and CAs. Per the authors, clinicians should modify the treatment plan of care to make certain that AAs and CAs are provided with "the most effective therapies possible so that potential for racial disparities in outcomes is minimized."[19(p1727)]

There are other research studies indicating that AAs were also discharged with lower functional outcomes compared to CAs using FIM scores. African Americans with stroke in Veterans' Administration IRFs had a significant longer LOS (p=.01) and a 1.5 lower motor discharge FIM score (p=.002) compared to CAs.[70] In a retrospective cohort study at a community-based IRF, AAs had a lower functional improvement FIM score at discharge compared to CAs.[21] A disparity in stroke rehabilitation care exists based on the previous finding that CAs with moderate and severe stroke received overall more minutes/day of therapy-related activities and interventions compared to AAs; however, there was not a significant difference in motor discharge FIM score between AAs and CAs.[20] In light of these findings, this study examined the ways a person's culture, race, and health status may influence the choice of and time associated with activities and treatment interventions within activities evidenced in the literature[20] that are associated with stroke rehabilitation care and outcome disparities from the perspectives of PTs.

Given that: (1) CAs with moderate stroke were not sicker than AAs, but still received more stroke rehabilitation care than AAs and CAs with severe stroke were sicker than AAs, but still received more stroke rehabilitation care than AAs,[20] (2) AAs have lower functional outcomes at discharge compared to CAs,[19,21,70] and (3) similar results in which race-related differential care was extended to persons with stroke[71] are

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found in the literature, gave support to pursue how and or why differential racialization is manifested in stroke rehabilitation. Differential racialization are methods by which different races or ethnicities are regarded and treated differently.[72] Extensive research has been conducted to establish the black box of stroke rehabilitation which attempts to classify the specific components of inpatient rehabilitation interventions.[12-16] There is no standardized application of care in inpatient rehabilitation because all persons with stroke are different, not only due to lesion location, but other contributing factors such as culture, race, health status, socioeconomic status, and environment. In addressing the black box of rehabilitation, culture, race, and cultural and racial background of the person with stroke and PT have not been considered as factors impacting stroke rehabilitation care and outcomes. Racial identity, cultural mistrust, and beliefs about one's race[39,64,73] and culture within the patient-provider interaction have a critical influence on rehabilitation outcomes for AAs[27,28] and may contribute to decreased success in rehabilitation outcomes experienced by AAwS. If the priority is to "determine the most active ingredients that affect patient outcomes"[12(pS2)] particularly for AAwS who tend to have lower inpatient rehabilitation outcomes, then culture, race, and cultural and racial background of those persons in the patient-PT relationship should be considered.

2.2 PATIENT-PROVIDER RELATIONSHIPS

There is limited scholarship in physical rehabilitation that identifies what components, if any, of the patient-PT relationship, termed *therapeutic alliance,* impact outcomes (level of function, alleviation of patient problem and or patient satisfaction). Therapeutic alliance, also known as working alliance, has its origins in psychoanalysis and is a collaboration between therapist and client to alleviate the client's problem.[74,75]

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Bordin argued that therapy effectiveness depends on the strength of the working alliance and that strength is a function of two constructs and how well they interconnect.[74] Those constructs are the demands of the working alliance and the personal characteristics of the therapist and client. Furthermore, Bordin refined three components essential to the working alliance: (1) agreement on *goals,* which in physical therapy should be patient-centered and valued,[76-78] (2) collaboration and relevance of the *tasks,* which should be linked to the goals, and (3) the nature of the relationship, in which *trust* or a *bond* can be more easily established if there is commonality in shared experiences and the client finds the tasks introduced by the therapist relevant in alleviating the problem.[74,75]

Results from two meta-analyses in psychotherapy ($r = .26$, $r = .22$) demonstrated that there is a positive relationship between the therapeutic alliance and outcome (treatment adherence, patient satisfaction, psychosocial and overall health, and physical function) and the relationship remains consistent despite other variables that may influence the therapeutic alliance.[79,80] In physical rehabilitation literature, there is a positive association between therapeutic alliance and patient treatment outcomes, based on a summary of 14 studies whose participants had diagnoses consisting of brain injury, cardiac, musculoskeletal, cardiac, and multiple complex conditions.[81]

If the intent is to eliminate disparities in stroke rehabilitation care and outcomes, and bonding or trust is a result of the patient's perception that the therapist has similar experiences and the patient feels that the interventions are relevant to her/his lived experiences,[74] it would make sense that culture, race, and or cultural and racial background of the patient and therapist is imperative to the therapeutic alliance. But, in psychotherapy and psychiatry, rather than provider culture, race, and or cultural and

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racial background, the emphasis is that providers be properly trained and demonstrate cultural competency and ethnic sensitivity to effectively diagnose and treat AAs,[82-84] as well as acknowledge their own cultural biases that may lead to a misdiagnosis.[83,84] Despite culture, race, and other related factors in the therapeutic alliance not being addressed in psychotherapy in the past,[82,85,86] they are being addressed in multicultural and cross-cultural psychotherapy.[83,87] More specifically, culture, race, cultural and racial background, and racism are being acknowledge as a priority in psychotherapy,[82,83,86,88] Furthermore, culture and race are of paramount importance in rehabilitation counseling and within that profession, multicultural and cross-cultural counseling protocols have been developed.[24]

There is a lack of evidence-based practice in physical therapy research demonstrating professional behaviors emphasizing social justice issues (biases and discrimination) and cultural understanding that are acknowledged through "trust, respect, and an appreciation for individual differences."[89(p1of2)] This acknowledgement in the vision statement of the American Physical Therapy Association (APTA) is referred to in Principle #1 of the Code of Ethics for PTs, which states that PTs shall:

> [1]A: act in a respectful manner toward each person regardless of age, gender, race, nationality, religion, ethnicity, social or economic status, sexual orientation, health condition, or disability. 1B: recognize their personal biases and not discriminate against others in physical therapist practice, consultation, education, research, and administration.[90(p1of2)]

Neither the Code of Ethics nor the Standards of Practice for PTs specifies, delineates, or addresses culturally-relevant therapeutic interventions or advocacy to eliminate health disparities or health care inequities.[90,91] There is an expectation to address culture and race morally in terms of ethics, but there is no foundation and or guidelines to address

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culture, race, and social justice issues in physical therapy practice involving diagnosis and treatment. It is apparent in the literature however, race is somehow a factor in the type of and time associated with activities and treatment interventions within activities chosen for persons with stroke.[20]

African American healthcare consumers are more apt to follow prescribed health practices when: (1) the provider is AA,[92] (2) they feel trust is established in the relationship, and (3) their opinions in the decision-making process are respected and valued.[29,93-95] In medicine, race in the patient-physician relationship is known as race concordance (similar) or race discordance (dissimilar). Patient-physician research however, varies how race concordance or discordance is related to quality of care and health disparities.[95-99] Race is not the only measure of concordance or discordance, but when race is the primary factor under study concerning medical encounters, in general, positive outcomes are associated with race concordance. Language, culture, gender, and socioeconomic status have also been studied.[97,100-103] These factors are known as social concordance and when perceived as common elements of shared identity, trust is greater in the patient-physician relationship.[104] The patient-physician relationship is improved upon when there are common beliefs and values about health care, and similar communication styles, general values in life, and spiritual beliefs.[95,101,104] The literature demonstrated however, that race is a central factor for disparities in care that exist when substandard care is perceived by the patient, particularly when physicians are CA and the patients are AA, physicians are AA and the patients are CA, and CA physicians have negative perceptions of patients who are AA.[93,100,104,105]

Biases that are developed through socialization processes, reinforced via media,

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and imposed by structural factors (policy), may produce subliminal stereotyping of individuals. Physicians associated patients' race with intelligence, feelings of alliance, clinical decision-making, and perceptions about behavioral risks and adherence to medical advice.[100,106] Perceived similarity by patients was strongly associated with satisfied care and intention to follow treatment recommendations.[104] Therefore, it was important to know if race, as a personal characteristic, has any role in the therapeutic alliance between the patient and PT, in addition to culture and other psychosocial or sociodemographic factors that may influence stroke rehabilitation care and outcomes.

2.3 RACE AND CULTURE

History. Race plays a major role in American social and political history, like no other civilization in the world. The conceptualization of race was grounded in science based on the notion that Caucasian skulls are larger than Native American or African skulls and therefore, it was proposed that Caucasians were presumed to be more intelligent because of larger brains within the larger skulls.[107] Race however, has been interconnected to moral values and beliefs, such that the pervasiveness of these values and beliefs have impacted the social outcomes for AAs in the United States since the inception of slavery in which health practices are rooted. English colonists had a well-established economy based on slave labor, which was deemed appropriate for Africans, being of lesser intelligence and therefore, the institution of slavery was justified because of racial subordination.[108,109] Slave owners provided and paid for all medical care for slaves because the South's economic success depended on a healthy slave population to cultivate crops.[110-113] With emancipation however, the health of Africans and AAs deteriorated because of a primitive health care system in which paid health care was tied

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to an economic enterprise.[114,115] Enslavement meant a provision of health care, whereas freedom did not, and thus, the beginnings of racial disparities in health from the incidence and prevalence of diseases to mortality for freed slaves.[114,115] For slave owners who suffered economically from the Great Migration North of AAs, and for those who were able to retain former slaves for plantation labor, their paternalistic attitude toward taking care of slaves for economic prosperity[113] dictated the South's health care, which was based on race and the moral values and beliefs about AAs at that time.

The health status of AAs changed as industrialization transformed the landscape of farming and the federal government became involved as the health of AAs evolved into a national concern. Hospitals were established and operated by the Bureau of Refugees, Freedmen and Abandoned Lands and seven medical schools with hospital affiliations were established between 1868 and 1904 by AAs and supportive CAs.[116,117] Moral values and beliefs that justified slavery now created a segregated health care system with the advent of separate health care facilities for AAs. The injustices of slavery that impacted social behavior and perceptions against a group of people because of race still lingers today in health care, albeit if not intentional, but covertly in medical encounters that may contribute to continuing health disparities between AAs and CAs.[108,118,119]

Race and Racism. *Race* has been defined as a "pseudo-biological concept"[23(p1208)] that is used to validate the disparate treatment of a person based on visible characteristics like skin color.[23] The American Association of Physical Anthropologists however, issued a statement that the biological concept of race is flawed and there is no genetic premise on which to base racial classification,[120] supporting the

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notion that race is a socially and politically constructed concept.[121,122] *Racism* is "any program or practice of discrimination, segregation, persecution, or mistreatment based on membership in a race or ethnic group."[72(p154)] Racism for the most part is not commonly blatant as it has been prior to, and during the Civil Rights era; but racism has taken on a new form called aversive racism that is subtle. The term aversive was coined because well-intentioned individuals would find it "aversive" to perceive themselves as, or be viewed as racially bias;[41,118,123] however, aversive racists recognize prejudice as detrimental to the relationship. Qualitative research indicated that racism and racial biases in health care were subtle nuances present in healthcare relationships as perceived by AA women.[124,125]

Prejudice and stereotyping are racial biases which can lead to discrimination.[41] Prejudice, stereotyping, and discrimination all have been suspected as underlying processes that contribute to health disparities, but how they contribute is not well understood due to difficulties in measuring perceptions of racial bias and discrimination, especially when implicit in origin. Specifically, *discrimination* is a differential action towards others based on their race,[122] whereas *prejudice* is a negative assumption, evaluation, or orientation towards a group or member of a group about the abilities, motives, and intentions of that group based on race.[41,122] *Stereotyping* is the "association or attribution of specific characteristics to a group and its members."[41(p478)] Skin color is a trait that activates implicit biases and stereotypical thoughts which corresponds to a social categorization of people based on held beliefs and assumptions that are consistently negative. This is particularly true for AAs based on the history of slavery in this country. These beliefs and assumptions constitute as nonclinical factors, which

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influence the medical encounter affecting clinical decision-making processes that may contribute to health disparities between AAs and CAs.[39,64,73] Physicians have more negative implicit attitudes and stereotypical thoughts towards AAs as being noncompliant patients and less likely to participate in rehabilitation therapy.[39,100,126] One study did not identify race of the physicians when ascertaining their perceptions of AAs versus CAs during medical encounters[100] and another did not explain how prejudice, clinical uncertainty, and stereotyping could contribute to health disparities.[39]

Culture. Culture is the full range of shared learned human behaviors that are a complex whole and comprised of knowledge, beliefs, art, laws, morals, customs, and any other capabilities acquired by humans as a members of society.[127] When defining culture, the Office of Minority Health has included hierarchies above individuals to include groups and institutions: "integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups."[128] Culture sets the precedence for how individuals perceive, receive, and adhere to health care information. Similar to race concordance, matching cultural characteristics of the patient-provider and public health and health care interventions with the patient may prove beneficial in decreasing health disparities between AAs and CAs.[101,129-131]

Minority populations have been stigmatized as lacking in cultural capital because outcomes associated with adhering to health care information and interventions were not positive.[132-134] Cultural capital is a term developed by Pierre Bourdieu to explain the disparities in educational attainment of children from different social classes.[135] Economic classes (upper, middle and lower) develop different cultural experiences,

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values, and beliefs within that class and this socialization process is tied to economic status.[135] Economic status often dictates social resources. A person's cultural capital although respected and beneficial within that class level may be viewed as inadequate by the dominating economic class.[135,136] Health care information and interventions however, are rarely informed by the cultural perspectives and behaviors of minority populations. Cultural traits have the potential to influence health behaviors. It is important that if the provider is not of the same cultural background and does not have shared lived experiences, the provider should demonstrate understanding and sensitivity relevant to the culture of the patient in the medical encounter. Verbal and nonverbal communications are critical factors in demonstrating cultural understanding and sensitivity to enhance the quality of care that is provided to and perceived by the patient.[101,130] Furthermore, racial bias on the part of the provider (symptoms ignored or misdiagnosed)[83] and cultural mistrust by AA patients (mistrust of a health care system dominated by CAs)[27,137] influence the clinical decision-making process[138] and rehabilitation outcomes.[27,28] The possibilities for positive health behavior change for AAwS stroke may be compromised when PTs lack an understanding of specific cultural variables present in the lives of their AA patients, which may bear significantly on their capacity to maintain recommended treatment strategies.

2.4 STROKE REHABILITATION: A QUALITATIVE APPROACH

Stroke disparities are often characterized quantitatively by differences in race, gender, geography, and socioeconomic status.[1,2,139,140] Furthermore, stroke disparities are also characterized by modifiable factors which are hypertension, diabetes, physical inactivity, and obesity.[2,52,141,142] Qualitative methodology has been used to determine understanding of,

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role in, and motivation towards stroke rehabilitation,[143-149] relationships with professionals,[143] what contributes to or barriers to recovery,[143,144] the confidence to recover,[143,145,146] how stroke is manifested and affects the quality life,[146,147] support systems,[147] and stroke knowledge.[148] There is a lack of qualitative evidence-based physical rehabilitation literature that verifies or disconfirms that culture, race, and or health status play a role in: (1) the clinical decision-making process used by PTs to deliver stroke care, (2) stroke rehabilitation care and outcomes disparities between AAs and CAs, and (3) the perspectives of AAs who are negatively impacted by stroke rehabilitation care and outcomes disparities.

Qualitative methodology is based on characteristics that were congruent with the intent of this study and furthermore, was supported by the theoretical concepts involving race and relationships. This qualitative study: (1) focused on phenomena which were inpatient rehabilitation experiences as they related to disparities in stroke rehabilitation care and outcomes between AAs and CAs, (2) prioritized the social aspects of culture, race, and patient health status in the patient-PT relationship and how culture and race were manifested in the relationship, (3) used purposeful sampling to address the persons involved in the phenomena, (4) emphasized data collection that described the phenomena and how or why the phenomena occurred from the perspectives of people who were experiencing the phenomena, and (5) acknowledged that data collection is a dynamic process requiring researcher interaction that was empathetic and understanding, but also neutral as not to sway responses.[149]

2.5 THEORETICAL FRAMEWORK

This was an exploratory study to ascertain the perspectives of AAwS and PTs

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about the role of culture, race, and health status in stroke rehabilitation care and outcome disparities between AAs and CAs. The emphasis of inquiry for AAwS was the patient-PT relationship and for PTs, the clinical decision-making process. Sociocultural Learning Theory (SLT), Critical Race Theory (CRT), Black Identity Development Theory (BIT), and Symbolic Interactionism Theory (SIT) informed the approach for establishing specific aims, the RQs, surveys, and the individual, paired, or focus group (FG) interview questions. Sociocultural Theory, CRT, BIT and SIT served as theoretical foundations to collect, analyze, interpret, and present the study findings.

Because culture is a learned process of socialization through generations in a group of people,[24,150,151] SLT was appropriate to frame the study pertaining to the cultural experiences of AAwS and the perceptions of their culture by PTs. Based on my experiences as an AA PT, SLT justified my assumptions that directed the development of the interview questions about the cultural experiences of AAwS and how PTs provided therapeutic interventions related to the cultural habits of the AAs. Sociocultural Learning Theory posits that learning is a socialization process requiring that the individual interacts with people, objects, and events in the environment.[152] Wertsch used the term *sociocultural* to explain behaviors or what he calls "mediated actions" because mental action or how one thinks is rooted in cultural, historical, or institutional settings.[153] African Americans share a distinct cultural heritage based on the history of America and therefore, the implications of history intertwined with racism and inequalities may have continued to impact on how AAs learn. McPhail and colleagues researched and found that AAs learn differently via a process that is universal, intuitive and person-oriented, whereas their White counterparts learn via an information-driven process that is chronological, investigative, and object-oriented.[154] Therefore, theories

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explaining the function and importance of race and race-related topics were paramount because race is a common factor in the socialization, culture, and learning of AAs.

Critical Race Theory has its origins in Critical Theory.[155] Critical Theory explains systems of oppression and how individuals or groups interact and react to each other.[156] Critical Race Theory focuses on race and how racism are interwoven within many levels and systems that effect racial minorities who exist in American society, particularly AAs.[122,157,158] At the foundation of CRT are six basic principles concerning race and racism.[72] These are: (1) that racism is ordinary and not unusual, (2) the current system of CA domination and privilege over racial minorities serves valuable purposes, known as "interest convergence" such as economic power, (3) race is socially constructed, (4) the dominant society (CA) demonstrates differential racialization at different times according to purpose, (5) intersectionality (race, gender, class, and sexuality) and anti-essentialism (there is plurality, or use of more than one characteristic in defining a person or group) exists, and (6) racial minorities communicate shared experiences via counter-narratives (stories from the perspectives of racial minorities) related to race and racism of which CAs are probably not aware. These six core tenets have been applied in public health to formulate race-conscious research designs, methodology, and interventions, and to explain the outcomes of those interventions.[155,159,160] Aspects of those applications can be applied to physical therapy practice, research, and education.

The use of CRT provided a language to explain the role of race, racism, cultural biases, and discrimination to describe the health inequities that exist for AAs. Race is the core of four CRT principles that served to address the overall study intent: (1) CA domination over racial minorities, (2) racism is ordinary and not unusual, (3) social construction and

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perpetuation of stereotypes and social norms perceived by the dominant culture, and (4) differential racialization.[72] In health care, providers are overwhelmingly still CAs despite population growth and diversity in the United States[131] and as previously discussed in medical encounters, physicians demonstrate aversive racist behaviors and cultural biases that impact clinical decision-making skills, thus possibly contributing to health disparities between AAs and CAs.[41,83,118,123,137]

In addition, CRT justified my assumptions that directed the development of FG questions based on two observations made. First, PTs in general exert an authoritative stance with AAwS and do not include them in goal-making and treatment processes during inpatient rehabilitation which is a key factor in the therapeutic alliance.[74] Second, the interactions I have witnessed between CA PTs and AAwS were representative of CA domination over and the perpetuation of negative stereotypes and social norms against AAs that impacted the rehabilitation process. And because of those negative perceptions, AAwS were treated differently, which I denote as aversive racism. Previous research indicated that during inpatient rehabilitation, stroke care and outcomes are different for AAs compared to CAs[19-21] and differential treatment may be the cause.

Race as an underlying theme of CRT also informed my choice of recruiting only AAwS as participants because of the AA-lived experience. In articulating the experiences of AAs, individuals must acknowledge plurality, known intersectionality,[72] in describing AAs and their experiences. The responses of the AAwS and PTs were analyzed to determine intersectionality[72] of culture and race, which are constructs being studied that may influence stroke rehabilitation care and outcomes. Last, as a tenet of CRT, the counter-narrative is a mechanism by which marginalized groups can express their experiences, for

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which an interview format is appropriate.[72]

How AAwS perceive and react to PTs and vice versa in the health care relationship was addressed in the context of race. Black Identity Development Theory and SIT were used to address the patient-PT relationship. Black Identity Development Theory has its origin in Racial Identity Theory (RIT). Racial identity is "a sense of group or collective identity based on one's perception that he or she shares a common heritage with a particular group."[161] Black Identity Development Theory was developed out of the necessity to explain how Blacks/AAs identified and perceived their selves racially as society begun to change in the 1960s and also, how CAs perceived Blacks/AAs differently.[162] Also, it was a time when CAs were being described as a racial group and not ascribing to any ethnic group, whereas Blacks/AAs were described as belonging to a racial and ethnic group.[162] The term 'African American' emerged in the 1960s, but was not accepted until the 1970s.[162] It is a way to describe persons of African heritage who are descendents of slaves and born in the United States.[162]

The term "African American" is used interchangeable with Black, but not all Black individuals are African slave descendents.[162] Yet, black skin color is a code to represent the historical implications of slavery, and has influenced the social agenda for racism, discrimination, stereotyping, and cultural biases that are present today in education, health care, and law as well as policies that dictate these institutions. Hence, the insufficient clarity of what to be called and why, further supported the development of BIT.[162] The Black experience is unlike any other in America and the experience informs the stages of racial identity for Blacks/AAs which are: (1) an absence of identity, (2) acceptance of an identity imposed upon AAs by CAs, (3) rejection of that identity

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constructed by CAs, (4) reconnecting with one's self or *Blackness*, and (5) redefining one's racial identity by internalizing all aspects of Blackness.[162] This developmental process is dynamic and ongoing, depending on social contexts in life.

A primary social context by which individuals exist is the development of relationships. Relationships require interaction of some sort to be effective. For the patient-PT relationship or therapeutic alliance to be effective, there should be an established trust or bond and patient-centered goals that are collaborative in nature and task relevant.[30,74,76-78,93-95] Helms however, purports that when race-related issues enter the relationship, the quality of the interaction will be influenced by the existing racial identities of the person in power and the subordinate,[161] which is the PT and patient, respectively. Skin color is the symbol that often dictates the tone of the relationship before issues of primary concern are discussed. Black skin color is the subordinate color that reflects negative ideologies of racial identity. Symbolic Interactionism Theory supports this fundamental concept that continues to be perpetuated in America's social history.[122,162-165]

Symbolic Interactionism Theory has three basic principles[156,166] that are applicable to the AA with stroke-PT relationship: (1) persons act towards something (race assumed by skin color) based on the meaning they have, (2) the meaning associated with skin color can be ascribed to social interactions with others or established social norms that develop or contribute to the perceptions about that meaning, and (3) the meaning can be altered by the interpretation and understanding of social interactions. Therefore, it is critical that during the evaluation process, the PT engages in a dialogue that is culturally relevant and empathetic towards AAwS and have an appreciation of and value the lived

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"Black" experience. Evaluation outcome can lead to a collaborative process of goal setting that is meaningful to AAwS. Furthermore, quality interaction may elicit other common shared values and beliefs held by the patient and PT that may further strengthen the therapeutic alliance in spite of race discordance.

The perception of one's self or self-concept is developed through social interaction. Self-concept is shaped by the reactions of others and the perceptions of those reactions during social interactions.[167] Self-concept is developed in the last stage of redefining one's racial identity.[167] Acceptance of one's self is a critical motive for behavioral change.[167] Therefore, the acceptance of that self (being Black/AA) and acknowledgement of that self by the persons in the race discordant health care relationship may not only eliminate the disparities in stroke care and outcomes extended towards AAwS, but may also lead to long term health behavioral change, thus reducing the risk of second stroke. Refer to Table 2.1 for a summary of theories comprising the theoretical framework.

2.6 CONCEPTUAL MODEL

African Americans have a distinct social history that has been imposed upon them by the false assumption that because of their race, they were less intelligent and relegated to an obligatory system of slavery. Their health status was directly tied with the economic and if not, moral justifications of slavery. Today, the evidence overwhelmingly supports that the disparities in health of AAs compared to CAs are in some way related to race.[19-21,39,42-45,47,49,51,52,54,58,62-65,70,71,73,83,94,142,164,165,168,169] The purpose of this study was to explore the perspectives of AAwS and PTs to determine how culture, race, and health status plays a role in inpatient rehabilitation stroke care and

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outcome disparities between AAs and CAs. Refer to Figure 2.1.

2.7 SUBJECTIVITY

Subjectivity is the process by which the researcher acknowledges, discusses, and takes into consideration experiences, beliefs, and assumptions that have framed the purpose for conducting the study and the researcher's relationship to the study in terms of biases and perceived truths.[149,170] I must have acknowledged and understood through reflexivity, how my culture, race, and lived experiences impacted the development of inquiry into the phenomenon and my views and understanding of the subsequent findings. Subjective experiences are important components that justify use of the interpretivist approach to frame the study using CRT and discuss the data. Phenomena can only be understood within the context in which they are studied,[149] and experienced. As a PT, I have had experiences or subjective truths that were contextually the same as other PTs, because I have worked on an inpatient rehabilitation unit and treated persons with stroke. But being an AA, I have experienced what I perceived to be as racism, which may be the same for AAwS participating in the study. The key was not to impart my subjective truths during the research process, but to remain neutral so that I understood and appreciated the perceived truths of the participants based on my lived experiences as an AA PT.

Race was the primary lens by which I viewed this study. I was socialized and developed cultural habits as an AA before becoming educated as a PT. I brought experiences of marginalization, discrimination, and learned behaviors of an oppressed person as I participated in this research as an inquirer, methodologist, and data analyst. This research was driven by my assumptions that culture and race are key factors in

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establishing trust in the patient-PT relationship and developing culturally-relevant interventions, which should parlay into AAwS maintaining health behaviors learned during inpatient rehabilitation after discharge. I assumed that because I am of the same race and raised in the customs of southern Gullah AAs, I held insider status, which meant ascertaining inpatient rehabilitation experiences that incorporated culture and race and other contextual factors, would be easier and with less hesitancy from AAwS.

In over 20 years of clinical practice, as a board certified clinical specialist in neurology, in every major rehabilitation setting across the continuum of care, I have been the "go to person" for advice on treating stroke with complex medical and impairment issues regardless of a person's race, ethnicity, class, and or gender. I have been particularly sought when the interaction has been strained by younger CA physical therapy practitioners and older AAs. Although I am sought to address the physical therapy-related problems, I feel age and race are key factors of which communication, respect, and or trust are primary problems. Southern older AAs need to be approached with respect despite education or socioeconomic status, because they value life experiences equally with educational and socioeconomic attainment (cultural capital). From personal experience, I know to address this group as "Mr." or "Mrs." or "yes sir or ma'am" which builds rapport and demonstrates respect.

I also assumed that because I am a clinical specialist of the same race, AAwS would be more apt to share their stories. African Americans with stroke assumed that I understood the behaviors that led to their current health status, which were rooted in cultural practices and social norms, as a result of discrimination and cultural biases because of race. Older AA adults are aware of discrimination in health care based on the mere existence of their skin color, and CA physical therapy practitioners may not be aware of, sensitive to, nor

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understand discrimination in health care. Cultural practices and social norms are factors related to positive health behavior change.[171,172] As an AA PT, who has been discriminated against solely because of race (differential racialization),[72] be it perceived or real, I was able to empathize with AAwS. I therefore appreciated the cultural practices and social norms of AAwS, respecting those experiences that reinforced behaviors, which have been detrimental to their health. The point was to: (1) acknowledge the stated perceived behaviors (which were representative by counter-narratives)[72] of AAwS, (2) ascertain from them, how physical therapy interventions can be respectful of those behaviors, and (3) suggest different healthier, but culturally-relevant behaviors, integrating and reinforcing them within the learned unhealthy behaviors.

I assumed that my professional background and educational attainment, as a physical therapy clinical specialist in neurology treating persons with stroke and the decision to return to school for a doctoral degree, demonstrated my expertise in practice and commitment to enhancing practice of all practitioners, by producing evidence-based research. It was not only important to ascertain perspectives from physical therapy consumers, but physical therapy providers to reveal the reasons how and why disparities exist in stroke rehabilitation care and outcomes. As a PT, who has worked on inpatient rehabilitation units, I empathized with PTs who perform their duties with limited resources and also take on external demands such as dealing with family coping struggles, playing the role of social psychologist, financial consultant, and being viewed as the expert to predict the level of functional return. These demands often take center stage ahead of the primary role of physical therapy interventions and activities to improve or restore function. I have experienced these external demands that often dictate physical

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therapy social interactions. These external demands and my advanced education in neurorehabilitation have shaped what I view as a human behavior problem in the health status of individuals that is complicated by culture and race. My role in this research as a PT was to use my educational attainment and neurologic clinical expertise to understand how and or why physical therapy practice norms and patient-PT characteristics (culture and race), roles, and interaction contribute to disparities in stroke rehabilitation care and outcomes.

2.8 EXPLORATORY QUALITATIVE APPROACH

This exploratory study was based on the constructivist and interpretivist approaches. Constructivism is the unique process of how individuals make sense of their reality, which should be considered valid and respected by the researcher.[149] The constructivist approach was ideal because I asked AAwS and PTs about "their reported perceptions, "truths," explanations, beliefs and worldview."[149(p132)] Furthermore, I wanted to discover if the participants realized that there are consequences to their constructions about culture, race, and cultural and racial background for them or individuals with whom they interact. Individual, paired, and FG interviews allowed me to understand how: (1) AAwS make meaning of their specific rehabilitation experiences, and (2) PTs make sense of the disparities in stroke rehabilitation care and outcomes as evidenced in the literature and based on their interactions with persons with stroke. A constructivist approach allowed for diverse perceptions and was a platform to encourage dialogue between me and the participants as well as between and among participants, thus producing a plethora of descriptive data to address the RQs. In line with SIT, this approach accommodated my contributions to the dialogue as moderator, knowing that I

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acknowledged my subjectivities, reflective stance, and accepted that my race and professional role may have impacted the conversations generated. The interpretivist approach complimented the constructivist approach because as an integral part of the data collection and analysis process, I presented the participants' truths integrating my perspectives as an AA PT.

Race and relationships were central themes of this research. Critical Theory is an interpretivist approach based on philosophical assumptions, frameworks, and the investigator's worldview of the subject matter.[155] Interpretivism in this context was defined from its origins in sociology, as strategies used to interpret the meanings and actions of the research participants according to their frame of reference,[173] particularly the "linguistic interpretations of actors' meaning."[173(p210),174,175] Physical Therapists' experiences as providers of care and racialized experiences of AAwS were key elements that justified the interpreting of answers from their viewpoint and articulating their responses. Conveying their perceptions, truths or explanations about inpatient rehabilitation experiences served as a foundation to support and justify my interpretation of participants' views and articulate them from my perspective as an AA, a PT, and a researcher. The interpretivist approach was twofold in that I as an AA PT appreciated the opinions of AAwS and PTs "as experts by virtue of the experiences and ideas they can share and their willingness to help explore the research problem."[176(p51)] Second, I used the findings from the pilot study to refine the survey, interview protocol, and the methodological process.

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Table 2.1 Theoretical Framework

Construct	Theory	Description
1. Social interaction 2. Learning 3. Culture	Sociocultural Learning Theory (SLT)	Learning is based on social interaction requiring mediated actions based on cultural experiences
1. Race 2. Culture 3. Patient-Provider Relationship	Critical Race Theory (CRT)	Explains race and how racism is interwoven within the many levels that ethnic minorities exist in American society; Provides dogmas that analyze and justify racial color blindness, subordination or domination of certain population groups and how the social construction of race affects relationships and institutional operations
1. Race 2. Culture 3. Patient-Provider Relationship	Black Identity Development Theory (BIT)	Emotional, cognitive and behavioral processes affiliated with being African American or Black; A dynamic nonlinear process by which African Americans/Blacks move from denigrating thoughts and behaviors associated with Blackness and idolizing Whiteness and ending with internalized positive thoughts and behaviors associated with Blackness
1. Race 2. Culture 3. Patient-Provider Relationship	Symbolic Interactionism Theory (SIT)	Analysis of how social meaning and reality are constructed through social interaction; Individuals in relationship act based on the perception of meanings and the reaction to the perception; Meanings change as perceptions change; Self-concept, symbols, and communication are key factors

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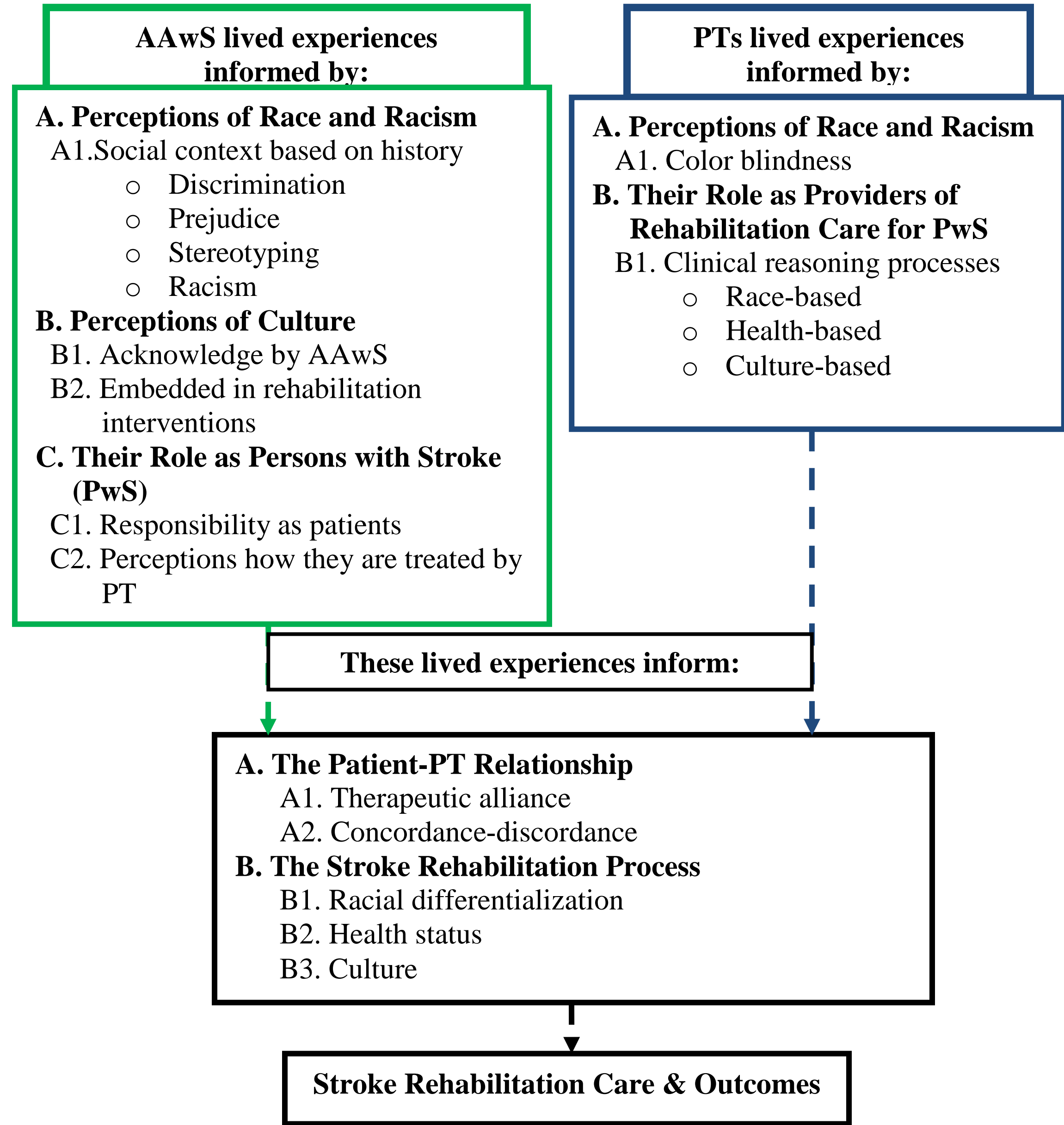

Figure 2.1 Exploring the perceptions of African Americans with stroke and physical therapists regarding how race, culture, and health status may influence stroke rehabilitation care and outcomes.

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CHAPTER 3

METHODOLOGY

3.1 METHODOLOGICAL APPROACH

This was an exploratory study using qualitative interviewing to discover the meaning of the lived experiences for individuals about a common event,[177] the inpatient rehabilitation program. This study used qualitative interviewing to explore: (1) the perceptions of AAwS regarding the ways in which culture and race may have played a role in their inpatient rehabilitation experiences, and (2) the perceptions of PTs regarding how culture, race, and health status of persons with stroke may impact treatment choices; the latter two being associated with the type of and time associated with activities and treatment interventions within activities as evidenced in the rehabilitation literature.[20] The use of individual, paired, and FG interviews supported the interpretive approach,[149,170] because interviews allowed for the accommodation of my lived experience as an AA and PT via the questions asked. From these common and shared experiences, I was better able to appreciate, understand, and interpret the meaning of the responses during the data collection and analysis process. I however, was a part of the interview process by facilitating diverse viewpoints without persuading what was said. Therefore, I attempted to retain a reflexive stance during the interview process through active listening, summarizing what was said, taking notes, and completing a postinterview reflection form within 24 hours of each individual, paired, and FG interview.

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In-depth interviews allow for the researcher to gain extremely personal information and institute probe questions to clarify information provided by the participant, which adds to the richness of the information generated.[170] Interviews produce a vast amount of information in a limited time period.[170] Via the interview format, a question is proposed and the answer generates data that is socially constructed and oriented.[170,178,179] Paired (two participants) in-depth interviews create an environment in which participants can discuss a "theme of mutual interest"[180(p2)] Furthermore, in a paired interview setting, because of similar backgrounds (culture, race, and disability), AAwS may have felt more comfortable talking about racism, discrimination, and cultural biases, if the topic has been stated and appeared as normal and validated by another who has had similar experiences.[178,181] Persons with stroke are familiar with paired experiences provided during inpatient rehabilitation therapies.[182-185] Some physical therapy interventions are done as a pair for modeling of therapeutic behaviors to motivate one another to fully participate in activities. Because of this previously paired experience during inpatient rehabilitation, paired interviews may have stimulated conversation as in modeling of therapeutic behaviors. Interview conversations evoked varied and rich descriptions of the rehabilitation experience based on questions asked, statements made, and individual lived experiences.

Focus groups were chosen to allow participants to engage in a group experience to share their views. Focus groups as a method of data collection were appropriate for this research because it entailed two key properties to generate data: (1) interview format and (2) group interaction.[149,178,181,186] The concept of race is socially constructed and racism is often neutralized and denied by the dominant culture by invoking color

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blindness – which is to emphasize other characteristics besides the race of an individual.[23] The object of FGs in this study was to engage participants in a conversation about race without overemphasizing race or directing their responses, thereby getting their perceived truths in an unassuming manner in a nonthreatening environment.

Focus groups are effective in generating a broad range of views on a specific topic, and a large amount of information in a short period of time, usually one to two hours.[149,178,186-188] Research indicates that the typical number of participants is six to 10,[189,190] with a maximum of 12.[187] A FG however, is defined as an interview with a small group of people, with group being the operative word.[149] The concept of triads was applied to this study because of the inability to recruit PTs and the limited number of PTs who meet the inclusion criteria.[191,192] Therefore, a minimum of three PTs participated in a FG.

Last, three to four FGs are recommended to produce trustworthy results as indicated by data collection saturation in which no more new information is produced.[179,187] Because of purposive sampling, this study however, did not attain three to four FGs of AAwS and PTs. And furthermore, the quality of this study was not dependent on the sample size, but rather as an exploratory study, the information generated by the limited number of participants. Per Patton,

> [v]alidity, meaningfulness and insights generated from qualitative inquiry have to do more with information-richness of the cases selected and the observational and analytical capabilities of the researcher than with sample size.[193(p185)]

Individual and paired interviews were chosen as a data collection method for AAwS due to the fact that there were not enough AAwS recruited to participate in a FG of three or more persons.

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The purpose of this research was to better understand the ways in which culture, race, and health status as variables (the latter two evidenced in the literature)[20] contribute to disparities in stroke rehabilitation care and outcomes. For AAs, racism may be an ordinary circumstance, whereas CAs may report not acknowledging race of AAs or unjust situations involving AAs as not to portray racist attitudes. Racism is difficult to eradicate based on the historical and social implications of skin color that are subliminally integrated into all levels of society, from policy to personal interactions.[23] In the use of recruitment materials and during all interviews, the intent was not to bias participants by acknowledging race as a possible reason for the disparities that AAs experience in stroke rehabilitation care and outcomes. Race however, cannot be ignored and special considerations were made when using qualitative methodology.

Recruitment materials must be representative of AAs.[194] The AAwS informational flier included the PI's photo. During the screening process of AAwS and AA PTs, AAs were encouraged to participate by informing them that their opinions mattered and needed to be included, because historically AAs are less represented in research due to discrimination in health care.[195] Shavers et al[196] wanted to determine if the knowledge of the Tuskegee syphilis experiment influenced participation in clinical research studies. For 46 % of AAs and 34% of CA, knowledge of the Tuskegee study would impact their decision to participate in future research and furthermore, 49% of those AAs indicated they would not be willing to participate in any future clinical research studies compared to 17% of CAs.[196] The results of the study also indicated that knowledge of the Tuskegee study caused 51% of AAs compared to 17% of CAs to demonstrate less trust towards researchers. Imperative to the research process is the

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establishment of trust between the researcher and the participant.[195] Race alone is not sufficient enough to establish trust, in light of the historical discrimination against AAs in research.[194] Therefore, I informed AA participants that I am a PT specializing in stroke care and a native South Carolinian from the Lowcountry. Social class however, as indicative by my professional and educational status, may have been a barrier to trust because AA participants may not perceive an AA moderator as a person of trust even though our skin color was the same.[194]

3.2 CONTEXTS

Participants. A purposeful criterion sampling of PTs and AAwS was used because the study required a specific type of individual who met certain criteria.[4,149] The second RQ was directed to PTs employed by IRFs based on the sample used in the rehabilitation literature from which the RQ was derived.[20] Physical therapists who self-reported as full-time (32 hours) employees of IRFs with a minimum of one year experience were eligible to participate.

African Americans were chosen because this subgroup of the population is disproportionately affected by stroke in South Carolina, and to express their opinions of culture and race as it related to the patient-PT relationship. The information generated can be conducive to shaping how PTs choose the type of and time associated with activities and treatment interventions within activities, particularly considering the cultural relevancy of those activities and interventions. Because of the historical implications of race in America, perceptions that AAwS may have had of their PT were important in establishing trust. Establishing trust may impact long term adherence to health behaviors that can decrease the risk of second stroke in AAs.[8,10] Critical Race

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Theory also informed the choice of recruiting only AAwS as participants because of their unique lived experiences and CRT provided a platform by which those experiences were told and valued as counter-narratives.[72]

African Americans, native to the Lowcountry have a distinct cultural background known as Gullah compared to AAs who live in the rest of the state. Gullah traditions influence language, dietary and health practices[197] that may impact the physical therapy experiences of AAwS differently compared to AAwS living outside the Lowcountry. Inclusion criteria were males or females who self-reported as African American or Black, 21 years of age or older, diagnosed with a unilateral stroke within one year of interview, one time admission and discharged from inpatient rehabilitation, and living in South Carolina. The following AAwS were ineligible for participation because they were unable to effectively participate in a conversation: (1) individuals with expressive or receptive aphasia, cognitive impairment, inability to independently provide consent and complete forms, and or verbalize thoughts, opinions, and feelings, and (2) persons who are legally blind, deaf, or have severe visual and or hearing impairments, impacting the ability to read or hear.

Site Selection. South Carolina was chosen for the site to conduct this research study because 3.1% of its adult population has been told by a health professional they have had a stroke, ranking the state 45th (five states >3.7%) in the nation in 2011.[198] Furthermore, AA South Carolinians are 61% more likely to die from stroke than CAs.[5] Nine IRFs providing stroke care in South Carolina were targeted to participate in the study: Greenville (1), Rock Hill (1), Florence (2), Murrell's Inlet (1), and Anderson (1), in addition to the targeted sites of Columbia (2) and Charleston (2). These facilities were

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chosen because: (1) of their history of admitting and treating persons with stroke, (2) all were accredited by the Commission on Accreditation of Rehabilitation Facilities or Joint Commission on Accreditation of Healthcare Organizations, and (3) seven of the nine were certified at some level in stroke rehabilitation. One IRF demonstrated full participation in that AAwS and PTs were recruited from the facility, one AA with stroke was recruited from a second IRF and PTs were recruited from a third and fourth IRF. The actual data collection sites were the homes of AAwS, the IRFs or the Public Health Research Center, at the University of South Carolina (USC).

Recruitment. In addition to the USC Institutional Review Board (IRB) approval, a facility-based IRB approval was required by seven IRFs. Once there was facility IRB approval, contact was made with inpatient rehabilitation directors/managers to establish study support and obtain verbal or written permission to engage in recruitment activities of AAwS and PTs. Inpatient rehabilitation directors/managers, case managers (CMs) and social workers (SWs) were mailed or hand-delivered up to 40 stamped envelopes containing a recruitment flier (Appendix A) and an invitation to participate letter for AAwS (Appendix B) as well as an extra copy of each not in an envelope. An AA occupational therapist was also solicited to assist in the recruitment of AAwS. African Americans with stroke who were participants in other stroke-related studies and signed a release to be contacted for future studies, were recruited via contacts made by the dissertation chairperson. Fliers and invitation letters to participate were also sent to presidents of graduate chapters of African American Greek letter organizations, pastors and healthy ministry liaisons of African Methodist Episcopal (AME) and Baptist churches, and neurology physician offices in areas of the IRFs. A statewide public

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service announcement was distributed by The Norman J. Arnold School of Public Health External Affairs and Public Information Department to various radio, television, and newspaper outlets throughout the state. The PI also appeared on a radio talk show, *Health, Wealth, and Happiness*, WGCV 620 AM, Columbia, South Carolina and a television talk show, the *Tammy Show*, Comcast Cable 2, Charleston, South Carolina to discuss the research topic and request AAwS to volunteer for the study.

For PT recruitment, inpatient rehabilitation directors/managers were mailed or hand-delivered fliers (Appendix C) and invitation letters to participate (Appendix D) based on the number of PTs who met the inclusion criteria. Contact was also made with PTs via email and recruitment documents were sent as an attachment.

Upon referral, I contacted the AAwS and conducted a phone screen to confirm their eligibility and willingness to participate in an individual or paired interview. I contacted PTs individually to confirm eligibility and willingness to participate or inpatient rehabilitation directors/managers completed this process. Each PT was mailed or emailed a copy of the study[20] from which the FG questions were derived to read and copies were available during FGs. After verifying eligibility and willingness to participate for AAwS and PTs, a date, time, and location for the individual, paired, or FG interview were made. African Americans with stroke and PTs met separately. All participants received $25.00 cash for participation, a thank you card, and a holiday card in the month of December.

3.3 INSTRUMENTATION

Survey. A personal data survey was developed to ascertain sociodemographic information from the AAwS and PTs that included age and gender for both groups.

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Specific to AAwS, information including caregiver status, where they were born and raised, highest level of educational attainment, current employment status, and self-rated health and rehabilitation care satisfaction was collected. Information pertaining to stroke history and ethnicity/race of their PT was obtained. AAwS were given assistance as needed to complete the survey (Appendix E). Similarly for PTs, highest level of educational attainment was obtained as well as number of years working in inpatient rehabilitation, advance practice status in neurorehabilitation, and ethnicity/race (Appendix F). Variables for the surveys were derived from information collected from the Survey on Disparities in Quality of Health Care: Spring 2001[199] and the documentation template of the Guide to Physical Therapy Practice by the APTA.[200]

Interview Protocol. A scripted protocol with semistructured open-ended questions was developed for the AAwS and PTs to ascertain the information set forth by the RQs. Critical Race Theory primarily guided the formulation of the interview questions as well as SIT, the latter for its emphasis on key factors that dictate mutual success in a relationship. Differential racialization, the method by which diverse races are regarded and treated differently is a tenet of CRT.[72] Therefore, interview statements and questions (Appendix G) were developed to elicit information about the cultural background of AAwS and their perceptions of: (1) PT inquiry regarding the cultural habits of AAwS and culturally-relevant treatment interventions, (2) trust and racial identity as factors to rehabilitation success, and (3) disparities in stroke rehabilitation care and outcomes between AAs and CAs.

The interview statements and questions (Appendix H) for the PTs were developed based on the findings from previous research in which the authors proposed that future

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research determine the clinical processes and or reasons used to determine stroke rehabilitation care and more specifically, differences in choice of treatments between AA and CA patients.[20] Physical therapists were asked to give their opinions regarding specific results from the study that may have been influenced by patients' health status or race. In addition, PTs were asked how they address the cultural habits of their patients. An issue statement which introduced the topic to be discussed preceded each question to be answered and discussed. Certain questions had scripted probes; however, probes emphasizing situational examples or comparative impressions were interjected as necessary to assure clarity and depth of the information. Refer to Table 3.1 (AAwS) and 3.2 (PTs) for a summary of the FG questions, related constructs, and affiliated theories.

Postinterview Reflection Form. The postinterview reflection form (Appendix I) was based on a document the PI received during a qualitative methodology class whose instructor of record served as a committee member. The PI received permission to modify the document (Michelle Bryan, Ph.D., Associate Professor, Educational Psychology, Research, and Foundations Programs, Department of Educational Studies, College of Education, USC, Email Conversation, May 2012). This form ascertained reflective subjectivities related to the process of data collection, content of the data collected, and the role the PI played as moderator as well as characteristics (race, gender, and professional background) that may have influenced interactions and responses during the interviews. The questions related to the PI's role and presence (state of mind, significance of interactions between group members and PI, and the PI's assumptions influenced by the data collected) were informed by and derived from SIT.

Focus Group Note Taker Form. Focus group field notes (Appendix J) taken by

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an AA research assistant (RA) experienced in FG methodology, qualitative analysis, and familiar with the study, were used to document detailed notes of the major themes discussed, observations that the digital-recorder did not capture (number of persons who agreed or disagreed during conversations), and body language (gestures and facial expressions during interactions). Notes taken by the RA were compared, discussed, and updated after FGs during a debriefing meeting and served as a method of validating the data and assured reliability of the data collection process.

3.4 DATA COLLECTION

African Americans with stroke received assistance as needed during the data collection process. All of the participants read the informed consent and only one AA with stroke required explanation of the information. All of the participants signed the informed consent prior to completing the demographic survey. All interviews were recorded using a digital voice recorder and lasted from 29 to 70 minutes. The PI served as the interviewer and FG moderator. A brief explanation of how the interview would proceed was explained for all participants. A semistructured interview format was used because further explanations and or clarification of statements or diverse views, were generated by interjecting a probing question(s) based on the participant's response to the initial statement. An issue statement was read to introduce the question content and each was shown on a separate power point slide via a laptop for individual interviews or projected onto a screen for paired and FG interviews using a projector. Given the sensitive nature of conversations that address race and racism, participants were made to feel comfortable to express their ideas or opinions related to the issues by reiterating that they and information shared would be de-identified in the dissertation, for presentations,

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and future publications.

Immediately following the individual and paired interviews, written notes were reviewed. Following the FGs, typed notes taken by the RA and the PI's written notes were discussed and compared, and changes were made as necessary to the typed FG field notes. Within 24 hours of all interviews, the PI replayed the digital recording, added comments to written or revised typed notes, and completed the postinterview reflection form. All notes taken during the interviews and the postinterview reflection form were added to a journal in successive order with additional blank pages added in case the PI needed to write any other reflections as a part of the journal. All hand written reflections were typed, printed, and added to the journal (Appendix K).

3.5 VERIFICATION OF VALIDITY AND RELIABILITY

To establish rigor in methodology and analysis, traditional quantitative approaches have qualitative counterparts: (1) internal validity (trustworthiness or credibility of data), (2) external validity (transferability), (3) reliability (dependability or consistency), and (4) objectivity (confirmability).[170] The PI addressed trustworthiness and dependability as methods to assure the rigor of this exploratory qualitative study. Because of the interpretive approach to this study, trustworthiness of the findings was judged according to the diligence of data analysis. Trustworthiness involves a dual approach integrating the coherence of participant's responses and the PI's interpretation of the findings.[201] To establish trustworthiness of the data, the PI supported the participants' perceptions with theoretical claims used to frame the study and by interpreting those perceptions conveyed by AAwS and PTs[202] using triangulation, member checking, and peer review.

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Triangulation. Triangulation is the use of multiple sources of data or data collection methods to confirm findings.[149] Pertaining to the participants, individual, paired, and FG interviews were the only method of qualitative data collection; however, a demographic survey, quantitative in nature ascertained information related to the RQs. Furthermore, the interview protocols addressed a different research question for AAwS and PTs; therefore, complementarity was used to address consistency in findings because two different RQs were addressed and the primary qualitative data collection method of interviews was used, complimented by the demographic survey.[203] A complementarity approach allowed the PI to gain a fuller understanding of the research problem from two different perspectives (AAwS and PTs) via interviews and then clarify the research results by finding commonalities and differences in opinions how and or why culture, race, health status, and cultural and racial background may have played a role in stroke rehabilitation care and outcome disparities.[204] Furthermore, variables and topics addressed via the demographic survey were used to strengthen the qualitative findings whether they were similar or different.

Member checking. The PI obtained permission to re-contact participants during the informed consent process to establish member checking. Member checking is the process of sharing data and interpretations with participants to validate what was said.[170,205] Participants were allowed to verify their responses during the data collection phase, confirm that what they said was actually what they meant,[170,206] and answer specific questions the PI asked in regards to interpretation of answers provided (Appendix L). All participants returned their transcripts except two AAwS. Implementation of this process assured that the respective truths of the participants were

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reflected in the PI's interpretations during the data analysis phase.

Peer review. The purpose of peer review is to establish credibility of the analysis process by determining congruency of coding and production of emergent themes from raw data and subsequent interpretations.[206] The RA who served as the note taker was also a peer reviewer for the first phase of the data analysis process. Using an *a priori* code list, the RA independently coded the first AA with stroke and PT transcripts in their entirety and a five page portion of the second PT transcript, all of which were compared against the PI's findings of the same data set. During the initial process of open coding, there was an attempt to have 70% agreement in codes. Percent agreement between two coders ranging from 70 to 90 is documented and deemed appropriate in qualitative research.[207,208] Initial intercoder reliability (ICR) was established and thereafter, the RA and PI discussed commonalities and discrepancies during this initial process, seeking 100% agreement on any code discrepancies. The second peer review activity consisted of an AA PT unfamiliar with the study and PI independently coding all of the transcripts using a codebook. Discrepant codes were discussed until 100% agreement was achieved. The PI updated the codebook categories, subcategories, and definitions after discussing each transcript before proceeding to the next. The third peer review activity consisted of two qualitative researchers serving as committee members checking the process of node development in NVivo 10,[209] data reduction, and theme development. This phase of the data analysis process was discussed between each qualitative researcher and PI until there was agreement of the resultant themes.

Dependability assured consistency in data collection process, thus contributing to accuracy in data content. Processes to establish dependability were creation of an audit

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trail, FG debriefing, and reflexivity.

Audit trail. An audit trail shows the process of how data was collected and managed starting from instrument development and refinement to corresponding data analysis changes, demonstrating the reasoning behind transformation of the data collection instrument and method and analysis.[170] An audit trail was developed by saving all feedback and dating successive edits for all forms and drafts for the dissertation proposal and defense, and manuscripts related to the study from committee members. Also, each successive codebook was color coded by edits and dates to demonstrate the progression of code relationships. If comments were added to reflexivity notes in the journal or the postinterview reflection forms, the information was color coded by edits and date. These documents served as an objective source detailing how ideas, thoughts, and the writing process were developed and pursued.

Focus group debriefing. Focus group debriefing allowed for a level of meticulousness to assure that subtle nuances would not be missed and there was clarity about the procedure of the interview process, and the PI's delivery.[194] Immediately following the FGs, the RA and PI compared and discussed notes that were independently taken. Any issues or questions about contents of the notes were clarified, so that there was mutual understanding of what needed to be modified for the next interview. Recommendations to improve future FGs were established and implemented based on the quality of the data generated. This activity also added to the trustworthiness of data collection for PTs and AAwS.

Reflexivity. Reflexivity is the process of acknowledging investigator bias towards the data, but incorporating one's identity and voice to interpret the findings from

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the perspectives of participants.[149,170] This process of self-reflection began by taking notes and completing the postinterview reflection form, requiring that the PI critically think about what was heard, seen, and felt during the interviews. A blank page was added behind each postinterview reflection form for the PI to add comments and revisit any issues that may have shed understanding on what was said by whom and why the topic came into existence within the conversation. Reflexive writing was a process to transform supportive documentation into data that was explained by the theoretical framework established to base and conduct the study, analyze and interpret the data, and link themes to the theoretical framework. Reflexive writing also validated the PI's truths about the data based on lived experiences without negating the truths of the participants. Reflexivity was an analytical process that forced the PI to be unbiased or objective towards the data during analysis, interpretation, and discussion.

3.6 ETHICAL ISSUES

Physical therapists, who were mostly CA and female (Byron Kirby, Program Manager, Office of Research & Statistics, S.C. Budget and Control Board, Email Conversation, May 11, 2012), may have felt uncomfortable when discussing the disparities in stroke rehabilitation, which were overwhelmingly negative for AAwS. Physical therapists may have felt that they were somewhat a contributing factor because the research demonstrated differential treatment towards AAs or I alluded to the fact that the inpatient rehabilitation experiences of AAwS are not reflective of their lived experiences and thus, possibly contribute to lower rehabilitation outcomes. This study may have had significant ramifications that may reflect negatively on PTs, particularly CAs because they may not be addressing their biases and or race and culture of AAwS which could benefit [their] potential

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to maintain and engage in physical activity and health behaviors learned during inpatient rehabilitation after discharge.

For AAwS, I had to be cautious in introducing the topic that their rehabilitation outcomes may be lower due to the color of their skin and or their health status. If AAwS perceived it as the former, they may have felt as if they did not get adequate care based on race alone and not because of the type of and extensive impairments caused by the stroke. My expectation was that as a result of their participation, in future interactions with PTs, AAwS would: (1) be proactive in stating what their life is like in terms of daily living activities so that PA and health behaviors can be integrated during physical therapy programs according to their lifestyle, and (2) request equitable physical therapy care as their CA counterparts with stroke. Now that they are aware of these issues by participating in this study, AAwS can perhaps decrease their risk of second stroke by engaging in culturally-relevant PA and health behaviors if addressed in future physical therapy experiences. This activism by AAwS, known as catalytic validity[210] however, was not the intended focus or outcome of this research.

I have a stake in this study based on my experiences as a neurologic clinical specialist treating persons with stroke. I feel it was an important piece of discovery that can inform health disparities in stroke rehabilitation. For AAwS, answering the questions can be a source of reflection of what potential they have to engage in culturally-relevant PA and health behaviors despite prior PA levels or health behaviors. Through qualitative interviewing, I gave them a platform to express what was favorable or not during the inpatient rehabilitation experience and how acknowledging those issues can continue to impact their daily lives.

I reiterated verbally over the phone and through the letter for member checking

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(Appendix L), that participation was voluntary and returning or not returning the transcripts would not result in any negative consequences. Furthermore, if having to read, edit, and answer questions that I asked were oppressive, burdensome, or otherwise uncomfortable, they did not have to return the transcript. I assured AAwS that any identifying information related to them would not be used in the dissertation, presentations, or subsequent manuscripts. Because qualitative research is probing in nature, to get to the essence of what individuals are thinking or their beliefs, it can produce anxiety or distress.[205] I perceived after the third and final attempt to obtain the transcripts, some level of tension became apparent and I no longer contacted two AAwS. Rarely was any tension revealed by the AAwS; however, during the interviews with PTs, there were often long pauses of silence. I had to rephrase questions and continue with what may have been perceived as a less threatening probe question or move on to the next issue statement and question.

Patient confidentiality was protected by procedures put in place during the research process, particularly by addressing procedures in the IRB-approved informed consent document. The transcriptionist signed a disclosure statement not to communicate or in any manner disclose publicly, information that was on the digital-recorder and that which was transcribed to a written format. If there was a risk of loss of confidentiality and anonymity, prior to commencing the paired and FG interviews, participants were asked to respect others privacy by not discussing any information outside the interviews and individual participants were asked not to discuss the content of the interviews. In addition, it was reiterated verbally, that information collected during the study would be kept confidential and participants' names and other identifying information would be changed

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to protect their identity in the dissertation, all manuscript drafts, manuscripts submitted for publication, and presentations. There were no potential financial risks to participate in the study. There were no significant physical or psychosocial risks in conjunction with the individual interviews; however, for the AAwS who did not return their transcripts, they may have thought otherwise. Answering questions about race and trust may have conjured negative images and memories about their inpatient rehabilitation physical therapy experience.

3.7 DATA ANALYSIS

The statistical package SPSS[211] was used to analyze the data. Descriptive statistics of central tendency was used to describe the mean and standard deviation for variables in the survey that described participant characteristics. In order to answer the RQs, a systematic process to analyze the data was followed, which consisted of data collecting, reviewing, coding, and categorizing, thematic development, and linking themes to theories and constructs through data interpretation, thus lending credibility to the findings. The process was as follows: (1) the PI took notes during all interviews and after the FGs, and the PI and RA compared, discussed, and updated notes independently taken, (2) within 24 hours, the PI added comments to the individual, paired, and FG interview notes taken while listening to the digital recordings and for all interviews, completed the postinterview reflection form; subsequent notes were added as needed, which became a part of the reflexivity journal, (4) the reflexivity journal included hand written notes that were later typed and subsequent notes were added as needed, (5) digital recordings were transcribed verbatim using a service (WD Ghostwriting Services, Goose Creek, SC) and all participants, locations, and other identifying information related to

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physical therapy experiences were de-identified, (6) all transcribed documents were reviewed with the corresponding digital recording for accuracy, (7) all participants were sent transcripts to clarify any content that was not understood by the PI and to verify their responses, (8) an a priori coding scheme was developed and the PI and RA independently coded the entire first AA with stroke and PT FG interviews and a five page section of the second PT FG interview for ICR and once established, if required, all discordant codes were discussed until consensus was reached, (9) the codebook was established and subsequently revised as transcripts were independently coded by the PI and an AA PT unfamiliar with the study; discordant codes were discussed until consensus was reached, (10) transcripts were recoded in NVivo 10;[209] the PI verified nodes (codes in NVivo 10) with previously established codes and documentation was created to explain why nodes were changed, added or deleted; annotations were created in NVivo 10 to explain the premises and context of nodes, (11) analyzed content was reduced through synthesis of parent (categories) and child (subcategories) nodes, whereby interconnected meanings of the data via [its] properties and dimensions were created to develop themes, and last (12) two qualitative researchers (committee members) checked node development in NVivo 10,[209] data reduction, and theme evolvement; issues related to thematic development were discussed as needed.

The data was analyzed using an inductive approach, which was based on the constructs and theoretical descriptions that comprised the theoretical framework, thematic content of the issue statements, and questions asked from the interview guides. The process to analyze the data however, was content analysis. Content analysis is reviewing text such as interview transcripts rather than observational field notes to discover primary

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and consistent topics and meanings of what is said by participants.[149] Important to content analysis is to recognize themes, a "categorical or topical form"[149(p453)] and patterns, a "descriptive finding".[149(p453)] This is done through a process of coding.

Codes are labels used to assign units of meaning to the data collected.[207] Open coding was an analytic process of examining and separating data into identifiable components of patterns or themes, categorizing data, and then linking the data conceptually to form themes.[212] The process of open coding was used to identify *what* was said by the participants pertaining to their behaviors and consequences of those behaviors, incidents, events, activities, relationships, and the conditions and settings associated with inpatient rehabilitation. Attention was also given to terms or phrases, meanings via symbols, feelings, and indigenous talk or Gullah terms.

The initial process of open coding required that the PI read through the first transcripts for AAwS and PTs and apply codes from the a priori codes to words, phrases, sentences, or paragraphs. New codes were created if the data did not fit into any of the a priori codes. The a priori codes and any other newly developed codes were defined and imported into the qualitative data analysis software, NVivo 10 as nodes.[209] A master node list, including definitions of each node was built in NVivo 10. All transcripts were downloaded into NVivo 10 and open coding proceeded via the computer. Thereafter, the master node list was organized into parent (categories) and child (subcategories) nodes.

Categories are "concepts that represent the phenomenon being discussed,"[212(p101)] which requires classification assigned through comparison. What constitutes membership in a category is that properties of the identified pattern and theme are "necessary and sufficient to confer membership to the category"[213(p253)] *Property* is the

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attribute or characteristic of what is analyzed and *dimension* is used to measure extension of the property along a continuum.[212,213] In the latter process of content analysis, data reduction occurred by creating interconnected meanings of the data via its properties and dimensions or theme development, which was distinctly different from categorization.[149,213]

Themes are interconnected meanings that are conceptually linked. Similarities or differences between themes identified within and between nodes were explored. Data interpretation occurred by linking established themes to theories and constructs used to frame the study and reflections written in the journal or as annotations in NVivo 10. This last step of data interpretation was from the perspectives of the AAwS, PTs, and the PI, accounting for differences or similarities, if any that existed between the PI and participants. Through content analysis of the data and by presenting a rich description of the data, the PI was able to: (1) detect how AAwS revealed issues of culture, race, health, and cultural and racial background of the PT that may have played a role in physical therapy experiences, and (2) ascertain the opinions of PTs regarding the role of culture, race, health status, and other contextual factors in rehabilitation care and outcome disparities between AAs and CAs with stroke.

In qualitative inquiry, the objective is to achieve saturation, defined as "no new themes, findings, concepts or problems, evidence in data".[214(p1230)] This concept has also been explained as redundancy.[215] Theoretical saturation refers to concepts, not data, and is the point when no further conceptualizations of the data is required because concepts are redundant with no significant conceptual variations, despite having more data to analyze when using Grounded Theory as a method for data analysis;[179, 213] however, this

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study did not use Grounded Theory. Dey prefers the term theoretical sufficiency, because the categories are well supported by the data and further data analysis would not require subcategories or creation of new categories.[170,213] For this study, having a limited cohesive population (PTs and AAwS) from which to draw a sample and having a specific sample to address the RQs, content saturation was achieved by completing a meticulous process of establishing categories and subcategories, connecting categorical properties and dimensions, and identifying how the categorical properties and dimensions are related to develop themes[213] using *all* interview data, known as content sufficiency.[213]

The term content sufficiency was appropriate for this exploratory study due to limited sample size and that content analysis was used to generate themes from limited data. Through multiple methods of content analysis (themes found within individual answers and intra-group comparisons) and a systematic and meticulous process of data analysis that included line by line analysis and repetitive coding of transcripts, the PI was assured of reliable content saturation with a limited data pool. Content sufficiency was derived from content saturation when the "process of generating categories [or subcategories as needed]…has been exhaustive [by multiple methods of content analysis and systematic data analysis within available data] rather than merely 'good enough'."[213(p40)] The available data came from a limited sample size and therefore, after multiple methods of content analysis and systematic data analysis, the content did not generate any "new interpretations of the available data,"[213,216] resulting in content "sufficiency" which parallels the concept of theoretical sufficiency posed by Dey[213] Thus, through content sufficiency, themes emerged.

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3.8 POSITIONALITY

Positionality is a term to define how the researcher is embedded in the research process by acknowledging any personal or professional information that may impact data collection, analysis, and interpretation.[149,170] As the moderator, I was engaged in the data collection process as an instrument influencing responses by who I am as a professional, what I said, body language, and characteristics that could not be changed such as race and gender. I was the best researcher for this study because of the following strengths: (1) insider status as an AA, (2) a board certified clinical specialist in neurologic physical therapy specializing in the treatment of stroke, (3) a former employee of many IRFs, and (4) being from the Lowcountry of SC, I am influenced by and partake in some of the Gullah traditions. I also have advanced education in studies that focus on rehabilitation disability and culture as well as the intersection of race, gender, class, sexuality, and culture. I also interact with friends and family who do not have advanced education, thus exposure to this socialization process enabled me to better construct questions for AAwS who did not have an advanced education. These strengths however, could have been weaknesses in terms positionality. As an AA PT, who has experienced racism in my social and professional interactions, I had to acknowledge biased perspectives regarding, and or preconceived notions about what the participants said despite asking probing questions. Because of my specialty in treating stroke and previous employment in inpatient rehabilitation, I attempted not to make assumptions of what happened during the rehabilitation process and asked probing questions for clarification.

My race and social class, indicative of my professional and educational background may have impacted the research study positively and negatively because of

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how I was perceived by AAwS. Although I am of the same race, AAwS may not have shared information because being AA, I should have known how race impacts them. African Americans with stroke may have held my specialization in high regard, but it also created a class difference in terms of status, which may have been another reason why AAwS felt I may have not understood their current situation. Furthermore, because I am able-bodied, AAwS may have felt that I did not understand their lived experiences, which may have been limited by their disabilities.

My professional background may have impacted the research study positively and negatively because of perceived power dynamics amongst my colleagues.[205] Physical therapists may have been intimidated by my level of expertise regarding the current evidenced-based neurologic practice and health disparities research literature. Despite currently working in inpatient rehabilitation, PTs may not have been aware of the disparities in stroke rehabilitation care.

Statistics indicated that at the nine IRFs, there were 34 PTs who self-report as White and one as Black (Byron Kirby, Program Manager, Office of Research & Statistics, S.C. Budget and Control Board, Email Conversation, May 11, 2012). There was concerted effort to make all interview questions race neutral; however, in order not to appear as racist, the PTs often reported they did not see color, but the person. The intention of the FGs with PTs was to create an environment in which they viewed me as an AA PT who appreciated their candor about the sensitive subject of race and culture in clinical practice. My intention was not to determine that PTs treat persons differently, but ascertain their perceptions why rehabilitation literature has found stroke rehabilitation care and outcome disparities between AAs and CAs, based on their experiences as PTs.

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Table 3.1 Conceptualization of Interview Questions for African Americans with Stroke

African Americans with Stroke			
Question	**Question Content**	**Construct**	**Theory**
1	1. AAwS acknowledge their culture 2. Probe questions: home, work, leisure, and health beliefs, values, and practices	Culture Race	SLT CRT, BIT
2	1. PT acknowledges culture of AAwS 2. Probe questions: home, work, and leisure	Culture Race	SLT CRT, BIT
3	1. Patient-PT relationship development	Patient-Provider Relationship Race Culture	SIT CRT, BIT SLT
4	1. Rehabilitation interventions related to AAwS culture 2. Probe questions: home, work, and leisure	Culture Race Patient-Provider Relationship	SLT CRT, BIT SIT
5	1. Cultural mistrust	Culture Patient-Provider Relationship	SLT SIT, CRT
6	1. Race concordance/discordance 2. Rehabilitation care	Race Patient-Provider Relationship	CRT, BIT SIT
7	1. AAwS treated differently by PT	Race Patient-Provider Relationship	CRT, BIT SIT
8	1. Differences in rehabilitation outcomes between AAs & CAs	Race	CRT, BIT

[a]AAwS=African Americans with Stroke
[b]PT=Physical Therapist
[c]AAs=African Americans
[d]CAs=Caucasian Americans
[e]SLT=Sociocultural Learning Theory
[f]CRT=Critical Race Theory
[g]BIT= Black Identity Theory
[h]SIT= Symbolic Interactionism Theory

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Table 3.2 Conceptualization of Focus Group Questions for Physical Therapists

Physical Therapists			
Question	**Question Content**	**Construct**	**Theory**
1	Differences in aspects of rehabilitation care for AAs[a] with stroke based on stroke severity	Race and Health	CRT[d] SIT[e]
2	Differences in aspects of rehabilitation care for CAs[b] with stroke based on stroke severity	Race and Health	CRT SIT
3	Clinical reasoning process to determine choice of treatment	Race and Health	CRT SIT
4	Description of AAwS[c] determines choice of treatment	Race	CRT SIT
5	Differences in rehabilitation outcomes between AAs & CAs	Race	CRT SIT
6	Acknowledge cultural habits of patient	Culture	SLT[f]

[a]AAs=African Americans
[b]CAs=Caucasian Americans
[c]AAwS=African Americans with Stroke
[d]CRT=Critical Race Theory
[e]SIT= Symbolic Interactionism Theory
[f]SLT=Sociocultural Learning Theory

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CHAPTER 4

RESULTS

4.1 MANUSCRIPT 1

Perceptions of African Americans with Stroke Regarding the Role of Culture and Race During Inpatient Rehabilitation Physical Therapy Experiences[1]

[1] Greene JV, Fritz SL, Bryan M, Friedman DB, Durstine JL, Newman-Norlund R. Article status – to be submitted.

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ABSTRACT

Title. Perceptions of African Americans with Stroke Regarding the Role of Culture and Race During Inpatient Rehabilitation Physical Therapy Experiences

Background. African Americans with stroke (AAwS) report inadequate amounts of exercise and higher rates of disability poststroke compared to Caucasian Americans (CAs). They are also more likely to have a second stroke compared to CAs. Research indicated that there is differential care extended to persons with stroke based on race. Distorted perceptions of race and culture in the patient-physical therapist relationship may contribute to the disparities in stroke rehabilitation care and outcomes for AAwS.

Objectives. The purpose of this study was to explore the perspectives of AAwS regarding the ways in which culture and race may have influenced their physical therapy experiences during inpatient rehabilitation.

Design. Qualitative exploratory research study

Methods. In-depth semistructured individual and paired (2 participants) interviews were conducted with a purposeful criterion sample of five AAwS. Interviews were digitally recorded, transcribed verbatim, and content analyzed.

Results. Data analysis revealed six themes: (1) self-acknowledgement, (2) shift in barriers to optimal health, (3) health cultured inferiority or subordination, (4) health outcome investment with a subtheme, culturally-relevant and functional activities, (5) issues of trust, and (6) race role interaction. These themes are all components of the patient-physical therapist relationship or therapeutic alliance in physical therapy practice.

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Conclusions. Future qualitative studies should examine how patient culture, race, and health status (the latter two evidenced in the literature) as perceived by physical therapists contribute to stroke rehabilitation care and outcome disparities that negatively impact AAs.

INTRODUCTION

Stroke occurs when interrupted brain blood flow causes an ischemic or hemorrhagic event.[2,31] It may impair cognition, mental status, vision, sensation, strength, and or balance resulting in decreased independence in daily living skills.[32] The prevalence of stroke is estimated at 7 million persons greater than or equal to 20 years of age in the United States.[1] Nationally, 4.5% of men and 4.4 % of women who are non-Hispanic African Americans (AAs) greater than or equal to 20 years of age have had a stroke compared to 2.4 % of Caucasian American (CA) men and 3.3 % of CA women.[1] In a study, weighted in favor of southeastern states and AAs, stroke symptoms were more likely among AAs compared to CAs.[33] Disparities occur in stroke from diagnosis to rehabilitation.

A health disparity is:

> …a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group;…or other characteristics historically linked to discrimination or exclusion.[36(p1of2)]

African Americans have a greater first time incidence of ischemic and hemorrhagic strokes, twice the rate of CAs[3,4,50-54] and at younger ages (20-54) compared to CAs.[4,50,52,55] Specifically, AAs are more likely to have ischemic strokes due to

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intracranial atherosclerotic disease, such as lacunar infarcts.[1,4,56-59] Caucasian Americans are more likely to have hemorrhagic strokes, extracranial carotid stenosis and atherothromboembolic events, and or cardioembolic events due to atrial fibrillation.[1,56-59] These disparities in stroke subtype, however, may result from deficient diagnostic evaluation.[60] When using diffusion-weighted magnetic resonance imaging for full diagnostic evaluation, similar proportions of ischemic and cardioembolic strokes exist between AAs and CAs.[60] African Americans with stroke (AAwS) are less likely to receive comprehensive noninvasive stroke testing[61] and rehabilitation evaluations.[62]

Following acute stroke, individuals are assessed for rehabilitation and placed based on clinical need, level of impairment, and financial and social resources.[15] Persons with stroke are the largest group of postacute rehabilitation consumers accounting for 17% of all inpatient rehabilitation admissions.[12,13] Stroke rehabilitation encompasses regularly planned therapeutic interventions involving flexibility, strength, balance and aerobic training, and learning and practicing daily living skills in physical therapy. Despite having inpatient rehabilitation, AAwS report inadequate amounts of exercise,[6] higher rates of disability poststroke,[7] and are more likely to have a second stroke compared to CAs.[8-11] Therefore, inpatient stroke rehabilitation programs should address stroke disparities.

Stroke rehabilitation effectiveness depends on patient characteristics and care and outcome processes; however, race and culture are not acknowledged as patient characteristics (as defined in the rehabilitation literature)[15] that contribute to factors of rehabilitation effectiveness. Furthermore, distorted perceptions of race and culture between AAwS and physical therapists (PTs), the lack of understanding cultural habits of

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AAwS, and the lack of culturally-relevant physical therapy interventions may contribute to stroke rehabilitation care and outcome disparities for AAwS. Research indicated that adherence to health behaviors will decrease stroke reoccurrence risk in AAs.[8,10] Positive health behavior change for AAwS may be compromised when PTs lack an understanding of specific cultural variables present in the lives of their AA patients, which may bear significantly on their capacity to maintain recommended protocols. If individuals are accepted to a rehabilitation facility, positive health behavior change is linked to provider trust and communication and participatory decision-making.[29,30]

Quantitative studies identified racial differences in stroke rehabilitation care and outcome disparities between AAs and CAs.[20,21] The rehabilitation experiences of AAwS may be influenced by racial and or cultural similarities or differences that exist between themselves and their PTs. The current stroke rehabilitation literature however, lacks qualitative research that explores racialized differences in treatment. Racial identity and cultural mistrust are critical factors that influence rehabilitation and may contribute to decreased success in rehabilitation outcomes experienced by AAwS.[27,28] The purpose of this study was to explore the perspectives of AAwS regarding the ways that race and culture may have influenced their inpatient rehabilitation experiences.

METHOD

Theoretical Framework

This exploratory study was developed through constructivism and interpretivism. Constructivism is the process of how individuals make sense of their reality.[149] Interpretivism is conveying participants' meanings and actions according to their frame of reference,[173] particularly the "linguistic interpretations of actors' meaning."[173(p210),174,175]

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Constructivism allowed for a platform that encouraged dialogue between primary author (PA) and the participants and between participants, thus producing a plethora of diverse descriptive data to address the research question. Interpretivism complimented constructivism in two ways: (1) as an AA PT, the PA presented the participants' truths integrating her perspectives, and (2) appreciated the opinions of AAwS "as experts by virtue of the experiences and ideas they can share and their willingness to help explore the research problem."[176(p51)] Sociocultural Learning Theory (SLT),[152,153] Critical Race Theory (CRT),[72] Black Identity Development Theory (BIT),[162] and Symbolic Interactionism Theory (SIT)[156,166] and the constructs of therapeutic alliance were used to establish the research question, methodology, and data collection method, and to analyze, interpret, and present study findings.

Because culture is a learned process of socialization through generations in a group of people,[24,150,151] SLT was appropriate to frame the study pertaining to the cultural experiences of AAwS and the perceptions of their culture by PTs. Learning is a socialization process requiring that the individual interacts with people and events in the environment.[152] The term *sociocultural* explains behaviors or what is called "mediated actions" because mental action or how one thinks is rooted in cultural settings.[153] African Americans learn differently via a process that is universal, intuitive, and person-oriented, whereas their CA counterparts learn via an information-driven process that is chronological, investigative, and object-oriented.[154] Therefore, theories explaining the function and importance of race and race-related topics are paramount because race is a common factor in the socialization, culture, and learning of AAs.

Critical Race Theory focuses on race and how racism are interwoven within many

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systems that affect AAs.[122,157,158] The use of CRT provided a language to explain the role of race, racism, cultural biases, and discrimination to describe the health inequities that exist for AAs. Race is the core of four CRT principles that served to address the overall intent of the study: (1) CA domination over racial minorities, (2) racism is ordinary and not unusual, (3) social construction and perpetuation of stereotypes and social norms perceived by the dominant culture, and (4) differential racialization - how diverse races are regarded and treated differently.[72] These principles can be applied to physical therapy practice which is reflective of health care provided in the United States. Providers are overwhelmingly still CA despite population growth and diversity[131] and in physician-patient encounters, physicians demonstrate aversive racist behaviors and cultural biases that impact clinical decision-making skills, thus possibly contributing to health disparities between AAs and CAs.[41,83,118,123,137] The last tenet, the counter-narrative is a mechanism marginalized groups use to express their experiences, justifying an interview format.[72]

How AAwS perceive and react to PTs and vice versa in the patient-PT relationship was addressed in the context of race using BIT and SIT. Black Identity Development Theory was developed to explain how Blacks/AAs identified and perceived their selves racially as society began changing in the1960s and also, how CAs perceived Blacks/AAs differently.[162] The term African American is used to describe persons of African heritage and descendents of slaves born in the United States.[162] African American is used interchangeable with Black, but not all Black individuals are African slave descendents.[162] Yet, black skin color is a code to represent the historical implications of slavery and has influenced the social agenda for racism, discrimination, stereotyping, and cultural biases present in health care. Black skin color is the

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subordinate color that reflects negative ideologies of racial identity. Symbolic Interactionism Theory supports this concept that is perpetuated in America's social history.[122,162-165]

Symbolic Interactionism Theory has three principles[156,166] applicable to the AA patient-PT relationship: (1) individuals act towards race (assumed by skin color) based on the meaning they have, (2) the meaning associated with race results from social interactions with others or established social norms contributing to perceptions about that meaning, and (3) the meaning is altered by the interpretation and understanding of social interactions. Therefore, critical to the evaluation process, is that the PT engages in dialogue that is culturally relevant and empathetic towards AAwS and appreciates and values the lived "Black" experience. Evaluation outcome should result in a collaborative process of goal setting meaningful to AAwS. Furthermore, quality interaction may elicit other common shared values and beliefs held by the AA patient and PT that may further strengthen the race discordant relationship.

Relationship development is a primary social circumstance for individuals. Relationships require interaction. An effective AA patient-PT relationship or therapeutic alliance has an established trust or bond and patient-centered goals that are collaborative in nature and task relevant.[30,74,76-78,93-95] When race-related issues enter the relationship however, the quality of the interaction is influenced by the existing racial identities of the person in power and the subordinate,[161] being the PT and patient, respectively. Skin color often dictates the tone of the relationship before issues of primary concern are discussed.

The patient-PT relationship requires social interaction. Self-concept is developed

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and shaped by the reactions of others and the perceptions of those reactions during social interaction.[167] Self-acceptance is a critical motive for behavioral change.[167] Therefore, accepting being Black/AA with stroke (self-concept) and acknowledgement of that self by individuals in the race discordant relationship may not only eliminate stroke rehabilitation care and outcome disparities of AAwS, but may also lead to long term health behavioral change, thus reducing stroke reoccurrence.

Research Design

Qualitative methodology has been used to determine understanding of, role in, and motivation towards stroke rehabilitation,[143-149] relationships with professionals,[143] what contributes to or barriers to recovery,[143,144] the confidence to recover,[143,145,146] how stroke is manifested and affects the quality of life,[146,147] support systems,[147] and stroke knowledge.[148] There is a lack of qualitative literature that verifies or disconfirms that culture and race play a role in stroke rehabilitation care and outcomes disparities that negatively impact AAs from their perspectives.

A semistructured interview format was used because further explanation or statement clarification, was generated by interjecting a probing question(s) based on the participant's response to the initial question.[170,176] In-depth interviews allowed the PA to gain extremely personal information, adding to the richness of the information generated.[170] Interviews generate answers that are socially constructed based on experiences.[170,178,179] Paired (two participants) in-depth interviews create an environment allowing participants to discuss a "theme of mutual interest"[180(p2)] Furthermore, during paired interviews, AAwS with similar backgrounds (culture, race, and disability), may have felt more comfortable talking about racism, discrimination, and cultural biases, if

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the topic had been stated, appeared as normal, and validated by an AA having similar experiences during inpatient rehabilitation.[178,181] Paired interviews simulate inpatient rehabilitation therapy dynamics. Therapy activities and interventions are done in pairs for modeling of behaviors to motivate another to fully participate.[182-185] Therefore, paired interviews had the potential to stimulate diverse interview conversations.

Researcher Subjectivity & Positionality

Subjectivity is the process whereby the researcher acknowledges, discusses, and takes into consideration experiences, beliefs, and assumptions that have framed the purpose for conducting the study and the researcher's relationship to the study via biases and perceived truths.[149,170] Subjective experiences were important components justifying interpretivism using CRT to frame and conduct the study and analyze and interpret data. Phenomena can only be understood within the context studied,[149] and experienced. The PA must have acknowledged and understood through reflexivity, how culture, race, and lived experiences impacted inquiry development into the phenomenon and perceptions of subsequent findings. The AA PA has experienced what is perceived as racism, which may be the same for AAwS participating in the study. The PA did not impart subjective truths during the research process, but remained neutral so that the participants' perceived truths were appreciated and understood based on the PA's lived experiences.

Positionality is how the researcher is embedded in the process by acknowledging any personal or professional information that may impact data collection, analysis, and interpretation.[149,170] The PA served as an instrument during the data collection process, influencing responses by what the PA stated, professional status, body language, and physical characteristics of race and gender that could not be changed. The PA's race and

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social class, indicative of professional and educational background may have impacted the study positively and negatively because of how the AAwS perceived the PA. Despite being the same race, AAwS may not have shared information with the PA because being AA, AAwS may have assumed the PA should have known how race impacted them.

Participants

A purposeful criterion sampling of AAs in South Carolina was used because they are disproportionately affected by stroke.[5,149] Inclusion criteria were persons self-reporting as African American or Black, 21 years of age or older, diagnosed with a unilateral stroke within one year of interview, one time admission and discharged from inpatient rehabilitation, and living in the state. The following AAwS were ineligible because they were unable to effectively participate: (1) have expressive or receptive aphasia, cognitive impairment, inability to independently provide consent and complete forms, and or verbalize thoughts, opinions, and feelings, and (2) legally blind, deaf, or have severe visual and or hearing impairments impacting the ability to read or hear.

Data Collection

The PA established contact at nine inpatient rehabilitation facilities (IRFs) accredited by the Commission on Accreditation of Rehabilitation Facilities or Joint Commission on Accreditation of Healthcare Organizations, with seven of the nine certified at some level in stroke rehabilitation for participant referral. The PA obtained verbal or written permission to recruit AAwS. Professional colleagues were emailed, hand delivered, or mailed stamped envelopes containing a recruitment flier and an invitation to participate letter for AAwS. Upon referral, the PA conducted a phone screen to confirm eligibility and willingness of AAwS to participate in a one-time individual or

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paired interview. Interviews were conducted at the IRFs or homes of AAwS. All AAwS received $25.00 cash for participating.

Participants read and signed the informed consent prior to completing a demographic survey. After the PA briefly explained interview proceedings, a semistructured interview (Appendix G - previously piloted) was conducted and digitally-recorded. An issue statement was read to introduce the question and shown on the laptop for individual interviews or projected onto a screen for paired interviews. Given the sensitive nature of conversations that address race and racism, AAwS were made to feel comfortable to express opinions by reiterating that they and information would be de-identified. Within 24 hours of all interviews, the PA replayed the digital recording, added comments to written notes, and completed a postinterview reflection form.

Data Analysis

All interviews were transcribed verbatim using a professional service (WD Ghostwriting Services, Goose Creek, South Carolina) and all AAwS, locations and other information describing therapy experiences were de-identified. Confidentiality was further ensured by labeling transcripts with letter and numerical identifiers and computerized documents were in a password-protected file. Transcripts were reviewed with the corresponding digital recording for accuracy and then sent to AAwS to verify responses and clarify any content not understood by the PA.

Data was content analyzed, which is reviewing interview transcripts to discover primary and consistent topics and meanings.[149] Content analysis requires theme and pattern recognition, "categorical or topical form"[149(p453)] and "descriptive finding,"[149(p453)] respectively. An *a priori* coding scheme was developed based on study theories and

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constructs. Codes are labels used to assign units of meaning to data.[207] Analysis required reading the first transcript and applying codes from the a priori list to words, phrases, sentences, or paragraphs. New codes were created for data nonapplicable to a priori codes from the initial and subsequent transcripts. All codes were defined and imported into the qualitative data analysis software, NVivo 10 (QSR International Inc, Cambridge, Massachusetts) as nodes.[209] A master node list, including definitions was created. All transcripts were downloaded into NVivo 10 and recoded. Thereafter, the master list was organized into parent (categories) and child (subcategories) nodes.

Categories are "concepts that represent the phenomenon being discussed,"[212(p101)] Categorization required classifying data through comparison and that properties of the identified theme and pattern were "necessary and sufficient to confer membership to the category."[213(p253)] *Property* is the characteristic of what is analyzed and *dimension* is used to measure extension of the property along a continuum.[212,213] Data reduction occurred by creating interconnected meanings of the data via its properties and dimensions, which is theme development, and thus, distinctly different from categorization.[149,213]

Themes are conceptually linked interconnected meanings. Similarities or differences between themes identified within and between nodes were explored. Data interpretation occurred by linking established themes to theories and constructs that framed the study and reflections written in the journal or as annotations in NVivo 10. This last step of data interpretation was from the perspectives of the AAwS and the PA, accounting for differences or similarities, if any existed between them. Through content analysis of data rich descriptions, the PA detected how AAwS revealed issues of race and culture and how those issues played a role in inpatient rehabilitation experiences.

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In qualitative inquiry, the objective is to achieve saturation, defined as "no new themes, findings, concepts or problems, evidence in data."[214(p1230)] Content saturation was achieved by completing a meticulous process of establishing categories and subcategories, and connecting and identifying how categorical properties and dimensions were related to develop themes,[213] using *all* interview data, known as content sufficiency.[213]

Verification of Validity and Reliability

In qualitative research, trustworthiness and dependability are established to verify rigor in methodology and analysis.[170] Trustworthiness of the findings was judged by the diligence of data analysis via member checking and peer review. Dependability was assured by consistency in data collection, thus contributing to accuracy in data content by creating an audit trail and reflexivity. Member checking is sharing data with participants to validate what was said.[170,205] All but two of the AAwS returned their transcripts. This process assured that participants' respective truths were reflected in data interpretations. Peer review establishes analysis credibility by determining congruency of data coding and production of themes and subsequent interpretations.[206] Using an a priori code list, a research assistant (RA) familiar with the study and experienced in qualitative analysis independently coded the first transcript, which was compared to the PA's codes. Percent agreement between two coders ranging from 70 to 90 is documented and deemed appropriate in qualitative research.[207,208] The initial intercoder reliability was 67%, but after discussing disagreements in coding, reliability improved to 83%. Thereafter, coding commonalities and discrepancies were discussed until 100% agreement was reached. Next, an AA PT unfamiliar with the study independently coded all of the transcripts

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using a codebook. Discrepant codes were discussed until 100% agreement was achieved. Codebook categories, subcategories, and definitions were updated after discussing each transcript before proceeding. Last, two qualitative researchers (co-authors) checked node development in NVivo 10,[209] data reduction, and theme evolvement. Issues were discussed as needed between each qualitative researcher and PA until there was agreement of the resultant themes. Audit trail shows the process of data collection and management from instrument development and refinement to corresponding data analysis, demonstrating the reasoning for data instrument, collection method, and analysis transformation.[170] An audit trail was developed by saving all feedback and dating successive edits for all forms and drafts for the research process. Each successive codebook was color coded by edits and dates to demonstrate code relationship progression. Comments added to the reflexivity notes and postinterview reflection forms were color coded and dated. These documents served as objective sources, detailing how thoughts and data interpretation evolved. Reflexivity is the process of acknowledging investigator bias towards the data, but incorporating one's identity and voice to interpret the findings from perspectives of participants.[149,170] Reflexivity began by taking notes during the interview, completing the postinterview reflection form, requiring the PA to critically think about what was heard, seen, and felt during the interviews. Subsequent journal entries and typed annotations in NVivo 10 were made during data analysis and interpretation. Reflexive writing as self-reflection, transformed supportive documentation into data explained by the theoretical framework, validated the PA's truths without negating the participants' truths, and served as a guide to promote objectivity during analysis, interpretation, and discussion.

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RESULTS

Descriptive Data

One paired and three individual interviews lasting 29-66 minutes were conducted with five AAwS (3 female, 2 male), mean age 62 (SD=3.3, median=61, range=60-68), and five months mean time since stroke (SD=3.9, range 1-10). Overall, AAwS rated their therapy experience satisfaction higher than current general health status (Table 4.1).

Themes

Six themes describing how culture and race played a role in physical therapy experiences of AAwS were discovered (Figure 4.1): (1) self-acknowledgement, (2) shift in barriers to optimal health, (3) health cultured inferiority or subordination, (4) health outcome investment with a subtheme, culturally-relevant and functional activities, (5) issues of trust, and (6) race role interaction. These themes are integral to the patient-PT relationship or therapeutic alliance. Therapeutic alliance has the potential to impact stroke rehabilitation care and outcomes disparities negatively impacting AAwS.

Self Acknowledgement. Self acknowledgement descriptors were statements that describe the behaviors, social networks, and resources shaping the life experiences of AAwS. Descriptors fell into subcategories that described some aspect of culture related to home life, work, and leisure activities:

> [g]row up to be respectful, um manners, um strive to try and be the best you can be and get an education, because an education because being a Black person, getting an education is the only thing that's gonna see you through, you know" (AAwS2).

Shift in barriers to optimal health. Participants answered questions about

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health beliefs, values, and practices prestroke and poststroke. There was a shift in knowledge and normative behaviors related to optimal health poststroke: “Where I think I mess up at, I ain’t take my medicine in five months. My blood pressure medicine and my sugar medicine-my diabetes medicine” (AAwS4), and “I just um…didn’t go to doctors. That was…um my main…uh…downfall. I was… had…a phobia when it came down to um…doctor” (AAwS1). Poststroke health beliefs, values, status, and self-perception and knowledge shaped behaviors of AAwS. There was tension between what was known and understood prestroke and what behaviors should have been performed or could perform prestroke and tension poststroke between what behaviors AAwS wanted to perform, but could not: “I was able to do whatever I wanted to do and now it’s…it’s a struggle because I have trouble with the arms and legs and I’m not able to…do the things that I used to do” (AAwS5).

Health cultured inferiority or subordination. This theme developed from three questions asked. Participants responded about topics their PT asked regarding home, work, and leisure prestroke. Responses emphasized cultural habits, family, and structural elements of the home: “Who did most of my cleaning, my cooking…and who took care of me.” (AAwS5); “if I like to play golf and all that.” (AAwS4); “Uh, they basically asked me about um…whether um…I’m com-comfortable being-coming back to work.” (AAwS1); and “she asked me how many steps and…about the bath tub… Did I have any handy cap…was I accessible to any rails or bars” (AAwS2). Participants answered how their treatment differed compared to other persons with stroke. For AAwS1, a comparison could not be made due to differences in stroke impairments and for AAwS5, interventions were equitable. The remaining AAwS reported issues associated with race,

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therapy quality and intensity, and PT effort: "sometimes I see them I saw with-with uh…Whites, a little bit better than they were working with me." (AAwS3); "I think time was the biggest factor…and the activities too…the quality…it was more or less…they [Whites] got more hard practice" (AAwS2); and "when ___ get to you ___ act like you, ___ don't wanna ___ just play over you a look like" (AAwS4). Participants answered why stroke rehabilitation outcomes are lower for AAs compared to CAs. The responses pertained to intrinsic characteristics of AAs: "we don't want no better for ourselves." (AAwS3) and "Our attitude." (AAwS2); cultural habits: "our health practices?" (AAwS2); and race associated inequitable treatment: "Whites [PTs] take up more time with Whites [patients] when they got stroke" (AAwS4).

Health outcome investment. Participants answered questions indicating how the PT got to know them better and what interventions were practiced or not related to prestroke living. Three AAwS responded that engaging in conversation while being pushed to the gym in their wheelchairs. Two AAwS however, felt there was too much talking and not enough interventions practiced pertaining to home life postdischarge: "Come in here…, ___ do more talking than anything else." (AAwS4), and "More or less…how to balance…laps…stepping off and stepping up on curbs" (AAwS2). All AAwS provided answers related to home structure and two had leisure specific responses. Overall, there was a lack of culturally-relevant therapies practiced except for one AA who had an AA PT: "We went through everything that…I was accustomed to doing" (AAwS5).

Issues of trust. Trust was not an issue for three AAwS when their primary PT provided care; however, for AAwS4, issues of trust were based on how he perceived and

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was treated by other therapists: "But uh, it seem like some of the other one…them other ones they like kind of scorn you or something like that you know." For AAwS2 and 3, trust was an issue based on the inequities in care given to them compared to CAs with stroke: "But then, when a White person had therapy, they actually did more" (AAwS2).

Race role interaction. Participants were asked how race may have played a role during their therapy. For AAwS1 and 5, race was not an issue, but encouragement provided by and the PT's positive attitude mentioned by AAwS5 contributed to excellent therapy. The remaining AAwS perceived the therapist providing the care as prejudice, racist, discriminatory, or indifferent towards them, and therapy quality as inequitable and outcome negative: "I think they got wrapped up in what they [PT and white patient] were talking about…and they just seem to forget me." (AAwS3), and "___ come in there and then half do ya…___ um…scorn Black people" (AAwS4).

DISCUSSION

Rehabilitation research demonstrated that disparities in stroke care and outcomes of AAs compared to CAs are some way related to race;[19-21,62,70,71] however, this qualitative study was the first to explore disparities in inpatient rehabilitation physical therapy from the perspectives of AAwS and verified that race discordance in the patient-PT relationship is a factor, but race does not operate alone. Race as a personal characteristic is important in therapy interaction, but the demands of the patient-PT relationship also contribute to therapy effectiveness.[74] The patient-PT relationship or therapeutic alliance is a collaboration between therapist and client to alleviate the client's problem.[74,75] Therapeutic alliance impacts outcomes, such as patient level of function or satisfaction and has three components: (1) agreement on *goals,* that are patient-centered

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and valued,[76-78] (2) collaboration and relevance of the *tasks,* which are linked to goals, and (3) the nature of the relationship, whereby *trust* is more easily established if there is commonality in shared experiences and the patient finds the tasks introduced by the therapist relevant in alleviating the problem.[74,75] Trust manifested as an issue and when care was culturally relevant and patient-centered and valued, the PT's race was irrelevant. African American healthcare consumers are more apt to follow prescribed health practices when they feel trust is established in the relationship and their opinions in the decision-making process are respected and valued.[29,93-95] Furthermore, AAwS perceived that the therapist was invested in them and their performance during therapy based on attention shown, time spent and quality of therapy provided. Hence, therapeutic alliance is an element of health outcome investment for AAwS.

Therapeutic alliance was an underlying domain of themes self-acknowledgement, shift in barriers to optimal health, and health cultured inferiority or subordination. As part of the therapeutic alliance, AAwS had to acknowledge their contributions to the relationship in knowledge, behaviors, and perceptions about themselves, the stroke and its impact on their lives, and the rehabilitation process. Self-acknowledgement had to account for lived experiences of AAs or they would not have been able to discern how they were treated differently in a race discordant relationship when accounting for patient similarities in stroke impairments. The AAwS in race discordant relationships gave examples how their cultural habits were not integrated into treatment. Research shows that matching cultural characteristics of the patient-provider and health care interventions with the patient may prove beneficial in decreasing health disparities between AAs and CAs.[101,129-131] If the PT however, is not of the same cultural background and does not

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have shared lived experiences, the PT should demonstrate understanding and sensitivity to the patient's culture during therapy. All AAwS in this sample acknowledged how their behaviors contributed to stroke and their behavioral changes poststroke; however, those in race discordant relationships expressed that their health-related behaviors or cultural habits were not integrated into therapies. Integration of prestroke behaviors or formation of new behaviors would have required collaborating on activities and interventions, which is vital to therapeutic alliance. Thus, collaboration could promote development and learning of health behaviors during inpatient rehabilitation that could be continued after discharge. Research has shown that complying with health behaviors will decrease second stroke risk in AAs.[8,10]

Three AAwS indicated that therapy time and quality were not to the level of their expectations for what they perceived they could do compared to other persons with stroke who were receiving more time engaged in more aggressive activities and interventions. This finding was supported in the literature that found whether having moderate or severe stroke impairments, CAs received more minutes/day in therapy activities and interventions within activities that were more advanced.[20]

Four AAwS shared they did not feel as if they had voice in collaborations determining goals and therapy treatment. A person's cultural capital although respected and beneficial, within class level may be viewed as inadequate by the dominating class.[135,136] The participants assumed that therapists should have known what needed to be done and how to get them better. For the most part, therapies were not culturally relevant and AAwS perceived they were often not engaged in activities that would get them better. Therefore, therapies were culturally irrelevant and furthermore, subordinate

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when compared to the quality (type and aggressiveness) and intensity (time) of therapy provided to CAs with stroke. None of the AAwS stated, however, that lower outcomes were caused by the actions of the therapist despite being shown racial differentialization in treatment. Four of the AAwS stated that lower outcomes were the fault of the AAwS. This thinking in AAs has proven to be commonplace. Skin color is a trait that activates implicit biases and stereotypical thoughts, which corresponds to a social categorization of people based on held beliefs and assumptions that are consistently negative. Lower outcomes could not be the fault of the therapist, because of the role race and power plays in relationships. When race-related issues enter the relationship, the quality of the interaction will be influenced by the existing racial identities of the person in power and the subordinate;[161] thus supporting the theme health cultured inferiority or subordination.

This exploratory study examined how culture and race influenced experiences of AAwS during inpatient rehabilitation and therefore, results are not generalizable. Limitations in recruitment and data collection were apparent. The recruitment process was hindered by the need to rely on professional colleagues to distribute recruitment materials to eligible participants. Four of five participants never received a packet and were recruited by other means. The time since stroke varied from one to 10 months; therefore, therapy details may not have been remembered to fully answer questions or questions may not have been understood. Two AAwS did not return transcripts; therefore, the PA did not have any comment(s) on statements requiring clarification.

This study found that therapeutic alliance factors play a role in stroke rehabilitation care and outcome disparities. From the perspectives of AAwS, their cultural habits and race, as well as therapist's race and the acknowledgment and

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integration of cultural habits in therapy by therapists are characteristics impacting therapy experiences. Culture and race were embedded in the themes of self-acknowledgement, shift in barriers to optimal health, health cultured inferiority or subordination, health outcome investment and subtheme, culturally-relevant and functional activities, issues of trust, and race role interaction, which all tie into therapeutic alliance as relationship components. The possibilities for positive health behavior change for AAwS may be compromised when distorted perceptions of race are manifested in the relationship and therapists lack an understanding of specific cultural variables present in the lives of AA patients, which may bear significantly on their capacity to maintain recommended protocols. Future qualitative studies should examine how patient culture, race, and health status (the latter two evidenced in the literature)[20] as perceived by PTs are associated with stroke rehabilitation care and outcome disparities that negatively impact AAs.

Mrs Greene, Dr Bryan and Dr Fritz provided concept and idea. Mrs Greene, Dr Bryan and Dr Friedman provided research design and data analysis. Dr Bryan, Dr Friedman, and Dr Fritz provided manuscript review. Dr Durstine and Dr Newman-Norlund provided consultation. Mrs Greene acknowledges Otis L. Owens, Ph.D.(c), MPH, research assistant, Joni Dunmyer, MS, and Donna Chisolm, PT, MS for their contributions to study.

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Table 4.1 African American with Stroke Characteristics

AAwS[a]	Age (y)	Sex	Hemi Side	Time Since Stroke (mos)	Caregiver	Education Level	Physical Therapist's Race	Rehabilitation Satisfaction	Health Status
1	61	Male	Left	2	Sister	Technical college	Caucasian	Excellent	Good
2	60	Female	Right	8	Daughter	Graduate courses[b]	Caucasian	Excellent	Good
3	60	Female	Right	10	Mother	Graduate courses[b]	Caucasian	Excellent	Very Good
4	62	Male	Left	4	Wife	Technical college	Caucasian	Good	Fair
5	68	Female	left	1	Self	Graduate courses[b]	African American	Excellent	Very Good

[a]AAwS=African American with stroke
[b]Did not complete graduate school

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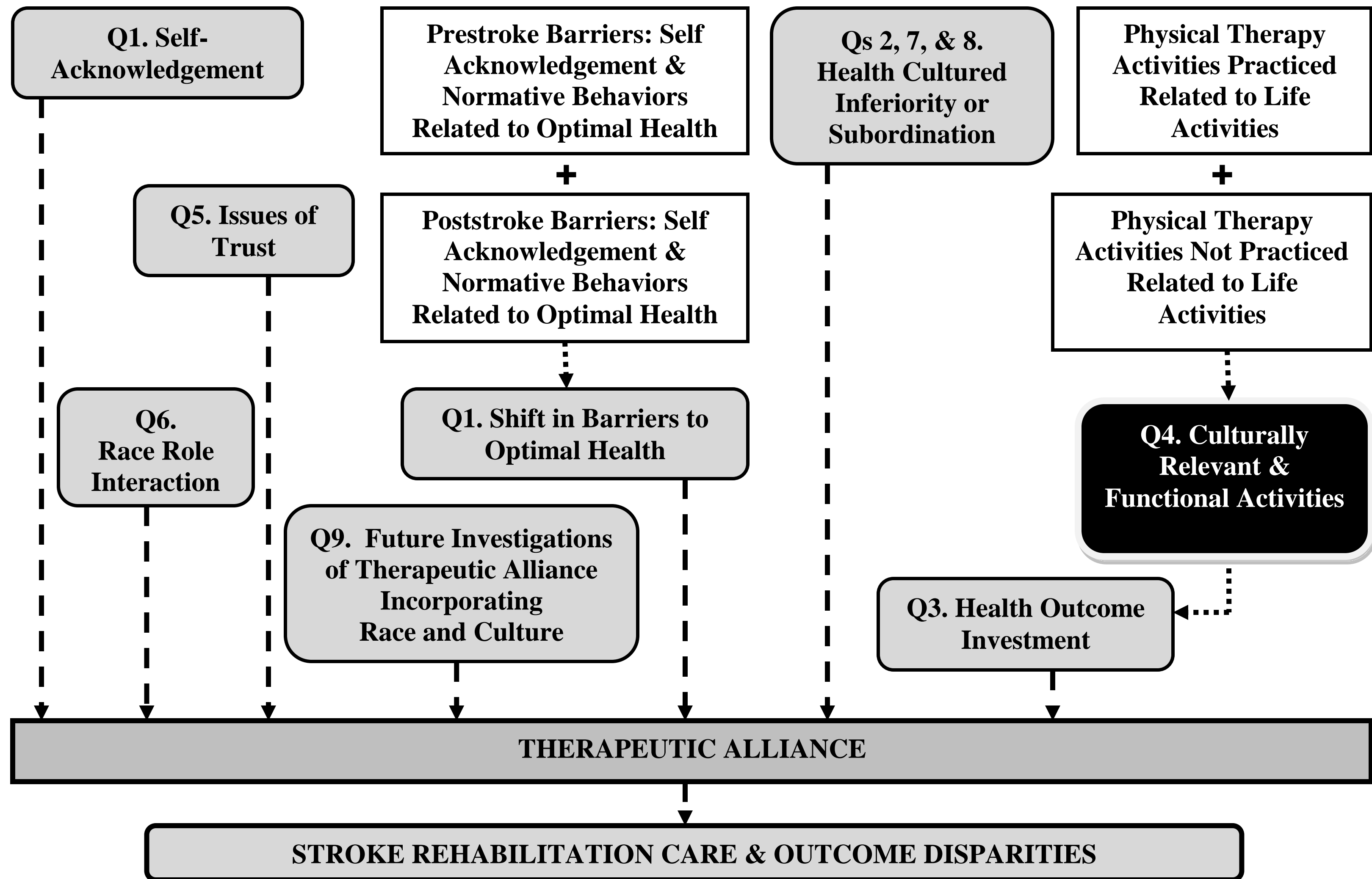

Figure 4.1 Themes derived from the perspectives of African Americans with stroke
Gray round rectangle = major themes; black round rectangle = subtheme; white rectangle = contribution to theme or subtheme

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4.2 MANUSCRIPT 2

Physical Therapists' Perceptions Regarding Culture, Race, and Health Status as Determinants of Differential Treatment in Stroke Rehabilitation [2]

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[2] Greene JV, Fritz SL, Bryan M, Friedman DB, Durstine JL, Newman-Norlund R. Article status – to be submitted.

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ABSTRACT

Title. Physical Therapists' Perceptions Regarding Culture, Race, and Health Status as Determinants of Differential Treatment in Stroke Rehabilitation

Background. Stroke disparities are often characterized by differences in race, geography, social aspects (socioeconomic status and education level), and modifiable factors (hypertension, diabetes, physical inactivity, and obesity). A study however, found that racial differences exist in stroke rehabilitation care and outcomes between African Americans (AAs) and Caucasian Americans (CAs). In addition to health status, the rehabilitation care of AAs with stroke may be influenced by cultural and or racial similarities or differences that exist between themselves and their physical therapists (PTs). Current stroke rehabilitation literature lacks qualitative research that explores racialized differences in physical therapy treatment.

Objectives. The purpose of this study was to explore the perspectives of PTs regarding how culture, race, and health status contribute to the disparities in rehabilitation care and outcomes for AAs.

Design. Qualitative exploratory research study

Methods. Two focus groups (seven and three participants) were conducted with a purposeful criterion sample of PTs. Focus group interviews were digitally recorded, transcribed verbatim, and content analyzed.

Results. Data analysis revealed six themes: (1) justice and equality, (2) family capacity, (3) patient-PT relationship, (4) health outcome investment, with a subtheme of physical

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therapy intensity, (5) systematic healthcare limitations, and (6) patient social health attributes. The diversity of these themes demonstrates the complexities involved in providing equitable care based on culture, race, and health status.

Conclusions. Future qualitative studies should investigate how physical therapy practice can accommodate the factors of culture, race, and health status in the delivery of care to eradicate stroke rehabilitation care and outcome disparities.

INTRODUCTION

An estimated 7 million persons are living with stroke in the United States[1] and African American (AAs), many who live in the southeastern region or Stroke Belt [2] are twice as likely to have a first-ever stroke compared to Caucasian Americans (CAs).[3,4] When accounting for patient differences, early and aggressive rehabilitation is better.[12,13] It is unknown however, which rehabilitation components impact inpatient rehabilitation outcomes for AAs who are disproportionately and negatively affected by stroke. Extensive research has been conducted to explain the "black box" of stroke rehabilitation.[12-16]

The black box is a metaphor (Gerben DeJong, Ph.D., FACRM, Senior Fellow & Director, Center for Post-acute Innovation & Research, National Rehabilitation Hospital & MedStar Health Research Institute, Email Conversation, February 24, 2012) to describe which rehabilitation components (length of stay (LOS) ,[17,18] time intensity,[18-20] or activities and treatment interventions provided to achieve activities[18-21]) contribute to stroke rehabilitation effectiveness. Stroke rehabilitation effectiveness depends on patient characteristics and care and outcome processes; however, culture and race are not acknowledged as patient characteristics contributing to rehabilitation effectiveness.[15] Instead, patient characteristics are defined as prestroke history, social support, cognitive

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functioning and illness severity.[15] Thus, although the black box acknowledges care based on stroke impairment, it fails to consider how perceptions of race and culture and culturally-relevant therapy may impact social interactions between AAs with stroke (AAwS) and physical therapists (PTs). If the priority is to "determine the most active ingredients that affect patient outcomes,"[12(pS2)] then culture, race, and health status should be considered.

Physical therapy lacks research demonstrating professional behaviors emphasizing social justice issues (biases and discrimination) and cultural understanding acknowledged through "trust, respect, and an appreciation for individual differences."[89] This acknowledgement in the American Physical Therapy Association's (APTA) vision statement is reflected in the Code of Ethics for PTs, Principle #1, stating PTs shall:

> [1]A: act in a respectful manner toward each person regardless of age, gender, race, nationality, religion, ethnicity, social or economic status, sexual orientation, health condition, or disability. 1B: recognize their personal biases and not discriminate against others in physical therapist practice, consultation, education, research, and administration.[90(p1of2)]

Neither the Code of Ethics nor the Standards of Practice specifies, delineates, or addresses culturally-relevant therapy or advocacy to eliminate health disparities or health care inequities.[90,91] There is an expectation to address culture and race morally in terms of ethics, but there are no practice guidelines addressing culture, race, and social justice issues. Research however, indicated race is somehow a factor in type of and time associated with activities and treatment interventions within activities chosen for persons with stroke.[20]

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In a study of six inpatient rehabilitation facilities (IRFs) across the United States, therapy varied by stroke severity and race.[20] *Therapy activities* were functional activities, whereas *therapy interventions within activities* were methods or modalities required to perform activities.[20] The IRFs' admission health status for persons with moderate stroke were similar between AAs and CAs; however, for persons with severe stroke, CAs were sicker compared to AAs. Overall, CAs with moderate and severe stroke received more minutes/day (significant) in more aggressive activities and interventions (transfers: $p<.017$, moderate and $p<.001$, severe; gait family caregiver education: $p<.001$, moderate; and community mobility balance training: $p<.009$, severe) compared to AAs, who had more minutes/day (significant) in less aggressive activities and interventions (wheelchair mobility: $p<.020$ moderate and $p<.001$, severe; wheelchair patient education $p<.016$, severe; and sitting motor control: $p<.030$, moderate). AAs however, had significant longer minutes/session or median session duration ($p<.001$, moderate and $p<.031$, severe). *Median session duration* "represents a specific predetermined time interval that each facility provides to their patients as a policy," (Susan D. Horn, Ph.D., Senior Scientist, Institute for Clinical Outcomes Research & Vice President, Research, International Severity Information Systems, Email Conversation, July 3, 2012). Per Dr Horn, "the clock was ticking with no activities, or there were rest periods between activities, or that the actual treatment time was not always provided according to the predetermined session time." Perhaps though, these findings suggest there was time during sessions AAwS were not engaged in activities or interventions, whereas CAs were engaged in activities and or interventions, justifying having higher minutes/day.

From the same dataset, CAs and AAs were given a greater number of sessions of

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interventions within activities that were both associated with higher and lower discharge motor Functional Independent Measure (FIM) scores.[19] If equitable and the appropriate therapy is given for clinical need in type and number of interventions, then functional outcomes should be equal and improved for AAs and CAs. Overall, however, CAs received more aggressive therapies and time in those therapies.[20] Per the authors, clinicians should modify treatment to assure AAs and CAs are provided with "the most effective therapies possible so that potential for racial disparities in outcomes is minimized."[19(p1727)]

Other studies indicated lower functional outcomes using FIM discharge scores for AAs compared to CAs. African Americans with stroke in Veterans' Administration IRFs had significant longer LOS (p=.01) and 1.5 lower motor discharge FIM score (p=.002) compared to CAs.[70] At a community-based IRF, AAs had a significant lower functional improvement FIM score at discharge (p=.02) compared to CAs.[21] Given that quantitative research demonstrated differential physical therapy care[18,20,71] and rehabilitation outcomes[19,21,70] are race-related, qualitative research should investigate why differential racialization (methods by which different races are regarded and treated differently)[72] exist.

Race is "ancestry and selected physical characteristics, such as skin color, hair texture and eye shape,"[22(p27)] and used to validate disparate treatment based on visible characteristics.[23] Race in the patient-physician relationship is described as concordant (similar) or discordant (dissimilar). Patient-physician research varies how race concordance or discordance is related to health care quality and disparities.[95-99] Race is not the only measure of concordance or discordance, but when considered the primary

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factor in medical encounters, overall, race concordance is associated with positive outcomes.[93,103,104,130,217] Language, culture, gender, and socioeconomic status are social concordance factors,[97,100-103] and when perceived as common elements of shared identity, trust is greater in patient-physician relationships.[104] Patient-physician relationships are improved when there are common health care beliefs and values and similar communication styles, general life values, and spiritual beliefs.[95,101,104]

Biases developed through socialization processes, reinforced via media, and imposed by policy, may produce subliminal stereotyping of individuals. Physicians associated patients' race with intelligence, feelings of alliance, clinical decision-making, and perceptions about behavioral risks and medical advice adherence.[100,106] Therefore, it is important to know how race impacts the therapeutic alliance or the patient-PT relationship. Researchers who found racial differences in stroke rehabilitation care and outcomes between AAs and CAs proposed that future studies investigate how race or health status is associated with PTs' choice of activities and interventions.[20]

Research indicated that health behavior adherence will decrease AA stroke reoccurrence risk.[8,10] Culture as health behavior is distinctive shared values, beliefs, and practices directly or indirectly associated with that behavior, and or influences acceptance and adoption of the health education message.[25] Distorted perceptions of culture and lack of knowing and understanding cultural habits may contribute to stroke rehabilitation care and outcome disparities. Therefore, the study purpose was to explore PTs' perspectives regarding how culture, race, and health status contribute to those disparities.

METHOD

Theoretical Framework

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This exploratory study was developed through constructivism, the process of how individuals make sense of their reality,[149] and interpretivism, conveying participants' meanings and actions according to their frame of reference.[173] Constructivism supported dialogue between primary author (PA) and participants and between participants, thus producing diverse descriptive data addressing the research question (RQ). Interpretivism complimented constructivism two ways: (1) as an AA PT, the PA presented participants' truths integrating her perspectives, and (2) appreciated PTs' opinions "as experts by virtue of the experiences and ideas they can share and their willingness to help explore the research problem."[176(p51)] Sociocultural Learning Theory (SLT),[155,156] Critical Race Theory (CRT),[72] Black Identity Development Theory (BIT),[162] and Symbolic Interactionism Theory (SIT)[159,169] and therapeutic alliance constructs were used to establish the RQ, methodology, and data collection method, and analyze, interpret, and present study findings.

Because culture is a learned socialization process through generations in groups of people,[24,150,151] SLT addressed AAwS' cultural experiences and PTs' perceptions of their culture. Learning is a socialization process requiring individuals interact with people.[152] *Sociocultural* explains behaviors or "mediated actions" because how one thinks is rooted in cultural settings.[153] African Americans learn differently via a universal, intuitive, and person-oriented process, whereas CAs learn by a chronological, investigative, and object-oriented information-driven process.[154]

Critical Race Theory explains race and how racism exist within systems affecting AAs.[122,157,158] Race, racism, cultural biases, and discrimination describing AA health inequities were explained using four CRT tenets: (1) CA domination over racial minorities, (2)

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racism is ordinary and common, (3) social construction and perpetuation of stereotypes and social norms perceived by the dominant culture, and (4) differential racialization.[72] These principles are applicable to physical therapy practice, reflective of health care in the United States. Providers are overwhelmingly CA despite population increase and diversity[131] and in patient-physician encounters, physician aversive racist behaviors and cultural biases impact clinical decision-making skills, thus possibly contributing to health disparities between AAs and CAs.[41,83,118,123,137]

How PTs perceive and react to AAwS in the patient-PT relationship was addressed using BIT and SIT. Black Identity Development Theory was developed to explain how Blacks/AAs identified and perceived their selves racially as society changed in the1960s and how CAs perceived Blacks/AAs differently.[162] African American represents a person of African heritage and descendent of slaves born in the United States often used interchangeably with Black; however, all Black individuals are not African slave descendents.[162] Yet, black skin color is a code representing subordination, symbolizing negative ideologies of racial identity associated with slavery and influences racism, discrimination, stereotyping, and cultural biases present in health care. Symbolic Interactionism Theory supports this concept perpetuated in America's history.[122,162-165]

Symbolic Interactionism Theory has three principles[156,166] applicable to the AA patient-PT relationship: (1) individuals act based on their meaning of race, (2) the meaning of race results from social interactions or established social norms, contributing to perceptions of that meaning, and (3) the meaning is altered by interpretation and understanding of social interactions. Therefore, it is critical PTs engage in dialogue that is empathetic towards AAwS and appreciate and value the lived "Black" experience.

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Evaluation outcome should result in collaborative goal setting processes meaningful to AAwS. Furthermore, quality interaction may elicit other common shared values and beliefs held by the AA patient and PT, strengthening the race discordant relationship.

Relationship development is a social circumstance for individuals, requiring interaction. An effective AA patient-PT relationship or therapeutic alliance has an established trust or bond and collaborative and task-relevant patient-centered goals.[30,74,76-78,93-95] When race-related issues enter the relationship however, interaction quality is influenced by existing racial identities of the person in power (PT) and the subordinate (patient).[161] Skin color often dictates relationship quality before discussing primary issues.

The patient-PT relationship requires social interaction, in which self-concept is developed and shaped by reactions and perceptions of reactions during social interaction.[167] Self-acceptance is a critical motive for behavioral change.[167] Therefore, accepting being Black/AA with stroke (self-concept) and acknowledgement of that self by individuals in the race discordant relationship may not only eliminate stroke care and outcome disparities of AAwS, but may also lead to long term health behavioral change, thus reducing stroke reoccurrence.

Research Design

Qualitative methodology has been used to determine relationships with professionals,[143] support systems,[147] stroke recovery contributions or barriers[143,144] confidence to recover,[143,145,146] and stroke knowledge, its manifestation and affect on life quality.[146,147,148] There is a lack of qualitative literature, verifying or disconfirming that culture, race, and health status play a role in stroke rehabilitation care and outcome

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disparities, negatively impacting AAs from the perspectives of PTs. Focus groups (FGs) were used to discover how culture, race, and health status impact therapy processes.

Focus groups were chosen allowing participants to engage and share views in a group experience. Data is generated by group interaction and interview format.[149,178,181,186] A semistructured in-depth interview generated further explanation or statement clarification by interjecting a probing question(s) based on participant response to initial questions. Interviewing allowed the PA to gain extremely personal information, accumulating rich and diverse socially constructed information.[170] Race is socially constructed and racism is often neutralized and denied by the dominant culture using color blindness – which is to emphasize other characteristics besides an individual's race.[23] The objective was to engage participants in a conversation about race without overemphasizing race or directing responses, thereby getting their perceived truths in an unassuming manner in a nonthreatening environment.

Focus groups are effective in generating a plethora of information on a specific topic in a short period of time, usually one to two hours,[149,178,186-188] with six to 12 participants.[187,189,190] A FG however, is defined as an interview with a small group of people.[149] This study used triads because of the inability to recruit PTs and the limited number of PTs meeting inclusion criteria.[191,192] Study quality was not dependent on the sample size, but the information generated by the limited number of participants. Per Patton,

> [v]alidity, meaningfulness and insights generated from qualitative inquiry have to do more with information-richness of the cases selected and the observational and analytical capabilities of the researcher than with sample size.[193(p185)]

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Researcher Subjectivity & Positionality

Subjectivity is the process whereby the researcher acknowledges, discusses, and considers experiences, beliefs, and assumptions that gave purpose for conducting the study and the researcher's relationship to the study via biases and perceived truths.[149,170] The PA must have acknowledged and understood through reflexivity, how culture, race, and lived experiences impacted study inquiry and perceptions of subsequent findings. Phenomena can only be understood within the context studied[149] or experienced. The AA PA has experienced what is perceived as racism, but also has had experiences or subjective truths contextually the same as PTs because of employment at IRFs, treating persons with stroke. The PA did not impart subjective truths during the research process, but remained neutral so that participants' perceived truths were appreciated and understood. The PA was socialized and developed cultural habits as an AA prior to physical therapy education. The PA brought experiences of marginalization, discrimination, and learned behaviors of an oppressed person to this research as an inquirer, methodologist, and data analyst. This research was guided by the PA's assumptions that culture and race are key factors mediating trust in patient-PT relationships.

Positionality is how the researcher is embedded in the study by acknowledging personal or professional information that may impact data collection, analysis, and interpretation.[149,170] The PA served as an instrument during data collection, influencing responses by what she said, professional status, body language, and unalterable characteristics of race and gender. Professional background may have impacted the study positively and negatively because of perceived power dynamics amongst colleagues.[205] The PA's level of expertise regarding the current evidenced-based neurologic practice

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and health disparities research may have intimidated PTs, who may not have been aware of stroke rehabilitation disparities despite currently working in IRFs. There was concerted effort to make all interview questions race neutral; however, in order not to appear as racist, the PTs often reported they did not see color, but the person. The intention during FGs was to create an environment, whereby the PA demonstrated appreciation of PTs' candor about race. The intention was not to determine that PTs treated persons differently, but ascertain reasons why research found stroke care and outcome disparities between AAs and CAs, based on their experiences.

Participants

A purposeful criterion sampling of PTs in South Carolina was used based on PTs employed by IRFs used in the study from which the RQ was derived.[20,149] Eligibility required full-time (32 hours) employment at IRFs with minimum one year experience.

Data Collection

The PA established contact at nine IRFs accredited by the Commission on Accreditation of Rehabilitation Facilities or Joint Commission on Accreditation of Healthcare Organizations, with seven certified at some level in stroke rehabilitation. The PA obtained verbal or written permission for recruitment. Directors/managers were emailed, hand delivered, or mailed a flier and an invitation to participate letter based on eligible PTs. Contact was also made with PTs via email and documents were sent as an attachment. The PA contacted PTs individually by email to confirm eligibility and willingness to participate in a one-time FG or directors/managers completed this process. Each PT was mailed or emailed a copy of the study[20] from which the FG questions FGs. (Appendix H - previously piloted) were derived to read and copies were available during

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PTs received $25.00 cash for participating.

Participants read and signed the informed consent prior to completing a demographic survey. After the PA explained FG proceedings, the FG was conducted and digitally-recorded. An issue statement was read to introduce the question, both projected onto a screen. A culture question was asked and others were derived from findings indicating significant differences in activities or interventions for AAs and CAs.[20] Given the sensitive nature of race and racism, PTs were made to feel comfortable to express opinions by reiterating that they and information would be de-identified. Written notes taken by the PA and those typed by the research assistant (RA) experienced in FG methodology were compared, discussed, and updated in typed format immediately following FGs. Within 24 hours, the PA replayed the digital recording, added comments to typed notes, and completed a postinterview reflection form.

Data Analysis

All interviews were transcribed verbatim using WD Ghostwriting Services (Goose Creek, South Carolina) and PTs and locations were de-identified. Confidentiality was further ensured by labeling transcripts with letter and numerical identifiers and computerized documents were in a password-protected file. Transcripts were reviewed with corresponding digital recordings for accuracy and then sent to PTs to verify responses and clarify content misunderstood by the PA.

Data was content analyzed, which is reviewing interview transcripts to discover primary and consistent topics and meanings.[149] Content analysis requires theme and pattern recognition, "categorical or topical form"[149(p453)] and "descriptive finding,"[149(p453)] respectively. *A priori* codes were developed based on study theories and constructs.

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Codes are labels used to assign units of meaning to data.[207] Analysis required reading the first transcript and applying a priori codes to words, phrases, sentences, or paragraphs. New codes were created for data nonapplicable to established codes. All codes were defined and imported into qualitative software, NVivo 10 (QSR International Inc, Cambridge, Massachusetts) as nodes.[209] A master node list, including definitions was created. All transcripts were downloaded into NVivo 10 and recoded. Thereafter, the master list was organized into parent (categories) and child (subcategories) nodes.

Categories are "concepts that represent the phenomenon being discussed,"[212(p101)] Categorization required classifying data through comparison and properties of identified themes and patterns were "necessary and sufficient to confer membership to the category."[213(p253)] *Property* is the characteristic of what is analyzed and *dimension* measures property extension along a continuum.[212,213] Data reduction occurred during theme development which is creating interconnected meanings of the data via its properties and dimensions.[149,213]

Themes, similar or different were explored between and within nodes and data interpretation occurred by linking themes to theories and constructs and reflections written as journal entries or NVivo 10 annotations. Data interpretation included similar or different perspectives of PTs and the PA. Through content analysis of data rich in descriptions, the PA detected how PTs revealed issues of culture, race, and health status.

In qualitative inquiry, three to four FGs are recommended to produce trustworthy results as indicated by data collection saturation, whereby no more new information is produced.[179,187] Because of purposive sampling and a limited population, this study did not attain three to four FGs. Content saturation however, was achieved by completing a

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meticulous process of establishing categories and subcategories, connecting and identifying how categorical properties and dimensions were related to develop themes,[213] using *all* interview data, known as content sufficiency.[213]

Verification of Validity & Reliability

To verify rigor in methodology and analysis in qualitative research, trustworthiness and dependability are established.[170] Trustworthiness was judged by meticulousness in data analysis via member checking and peer review. Dependability was assured by data collection regularity, thus contributing to truthfulness in data content via an audit trail, FG debriefing, and reflexivity. Member checking is sharing data with participants to validate responses, assuring data interpretations reflect their truths.[170,205] All transcripts were returned. Peer review establishes analysis credibility by determining congruency of data coding and production of themes and subsequent interpretations.[206] Using a priori codes, the RA who is also experienced in qualitative analysis, independently coded the entire first and five pages of the second transcript, which were compared to the PA's codes. Percent agreement between two coders ranging from 70 to 90 is documented and deemed appropriate in qualitative research.[207,208] The first transcript's initial intercoder reliability (ICR) was 53%, but after discussing disagreements in coding, reliability improved to only 55%. For the second transcript, ICRs were 29% and 49%, respectively. For both transcripts, coding commonalities and discrepancies were discussed until 100% agreement was reached. The RA was unfamiliar with physical therapy coding terms compared to the PA, thus contributing to low ICR. Next, an AA PT unfamiliar with the study independently coded all of the transcripts using a codebook. Discrepant codes were discussed until 100% agreement

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was achieved. Codebook categories, subcategories, and definitions were updated after discussing each transcript before proceeding. Last, two qualitative researchers (co-authors) checked node development in NVivo 10,[209] data reduction, and theme evolvement. Issues were discussed as needed between each qualitative researcher and PA until there was agreement of resultant themes. Audit trail shows the process of data collection and analysis management, demonstrating the reasoning for data instrument, collection method, and analysis transformation.[170] An audit trail was developed by saving all feedback and dating successive edits for all forms and drafts. Successive codebooks were color coded by edits and dates, demonstrating code relationship progression. Comments added to reflexivity notes and postinterview reflection forms were color coded and dated. These documents served as objective sources, detailing how thoughts and data interpretation evolved. During FG debriefing, notes taken by the RA which detailed major themes discussed, observations the digital-recorder did not capture (number of persons agreeing or disagreeing), and body language (gestures and facial expressions) were discussed with the PA. Notes validated and assured data collection process reliability. Reflexivity is the process of acknowledging investigator bias towards data, but incorporating one's identity and voice to interpret findings from the perspectives of participants.[149,170] Reflexivity began by taking FG notes and completing postinterview reflection forms, requiring the PA to critically think about what was heard, seen, and felt and ended with journal entries and typed annotations in NVivo 10 made during data analysis and interpretation. Reflexive writing as self-reflection, transformed supportive documentation into data explained by the theoretical framework, validated the PA's truths without negating the participants' truths, and served as a guide to promote

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objectivity during analysis, interpretation, and discussion.

RESULTS

Descriptive Data

Two FGs (55 and 66 minutes) were conducted at an IRF and the University of South Carolina with seven and three physical therapists, respectively; mean age 46 (SD=13.5, range 26-62); sex (8 female, 2 male); and 9.8 years mean time of IRF employment treating patients with stroke (SD=8.4, range 1-24). No PTs completed a neurology residency, and one was certified in neurology by the APTA's American Board of Physical Therapy Specialties. Levels of cultural competency varied among the PTs (Table 4.2).

Themes

Six themes were revealed (Figure 4.2): (1) justice and equality, (2) family capacity, (3) patient-PT relationship, (4) health outcome investment, with a subtheme of physical therapy intensity, (5) systematic healthcare limitations, and (6) patient social health attributes. These themes indicate diverse and complex issues regarding racialized stroke treatment.

Justice and equality. Responses revealed admission of having biases and assumptions about or stereotyping patients. Caucasian American PTs reported they do not see race, but the person, and did not expound upon how they see the person in terms of lifestyle or cultural habits, which could have been incorporated into therapy: "I don't really look at color" (PT1) and "there may be some biases too" (PT9). One AA PT however, reported having to educate CA male PTs about abilities of AAwS: "have a tendency to be uh…less respondent to the Black community um…the Black patients in

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providing them with more uh…aggressive … type of activities" (PT10). Another AA PT was able to cater therapy to AAwS because of shared identities: "I really go a lot in depth, probably more so with…with Blacks because some-most have a tendency to have kind of a same type of background" (PT8).

Family capacity. Disparities in AAs receiving less family education and less aggressive therapies compared to CAs were attributed to family availability, involvement, and demands including patient demands: "patient-family um involvement in those that are there on site willing to uh…to intervene with-with the patients" (PT10); and

> [b]ut certain White families really, really want the person to be ambulatory and that seems to be a major value situation, whereas in other cultures I've seen less concern about that person being totally ambulatory (PT9).

Patient-PT relationship. This theme developed from intrinsic and extrinsic characteristics of patients and PTs. Example of an intrinsic patient characteristic was motivation, but socioeconomic, education, and physical activity level, and obesity were common extrinsic factors impacting how AAwS were perceived: "there is a less tendency to invest more time with patients that do have um…the m-the m-the morbid obesity or" (PT10). Therapist intrinsic characteristics were motivation levels, perceptions of patients and potential to recover, and how to do treatment, whereas extrinsic characteristics were modifiable and nonmodifiable factors (race, age, gender, and skill level):

> [i]t doesn't seem like the-Af-the Black patients in this study were maybe challenged as much to do meaningful activities. I think we are can all be guilty of that depending on attitude, motivation (PT9).

Health outcome investment. This theme was comprised of patient,

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family/caregiver, and PT education, patient and PT cultural competency, therapy cultural relevancy and quality (minutes and aggressiveness), and patient goals and values. For PTs who invoked color blindness, educating the patient about cultural habits and being educated about [them] were not an issue unless cultural habits were impacting sessions. For PTs who practiced a client-centered approach, treatment included educating the patient how their cultural habits contribute to stroke and modifying and integrating cultural habits into therapy: " get an idea of what their cultural preferences are and if I can accommodate those preferences within the treatment but also be intense" (PT9).

Systematic healthcare limitations. This theme indicated why treatment was less aggressive and outcomes were lower for AAs compared to CAs. Staffing issues, payor source, and ethical practice were all related to healthcare policy stipulating time requirements for Medicare patients. Medicare patients were seen if short staffed, but PTs acknowledged that indigent or Medicaid patients were given longer LOS. Wheelchair mobility training was a common less aggressive therapy related to safety and healthcare policy provided to AAs, despite being less sick or equally as sick as CA:

> [U]m, so maybe its that-since they're higher in their FIM scores, they can get themselves down to the gym quickly, they're going to do the wheelchair mobility and go ahead and clock it as an activity because they're doing it (PT6).

Patient social health attributes. This theme was an aggregation of patient characteristics contributing to rehabilitation care and outcome disparities. Goal setting was dependent on prior and current functional levels. Patient goals were emphasized, but with no expectation to exceed the prior functional level. Assumptions were made about health status and practices warranting change, but no indications of understanding why

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they existed by asking patients, lending to patient cultural capital: “We can’t make them better than what they were” (PT1).

DISCUSSION

Rehabilitation research has demonstrated racial differences in stroke care and outcomes between AAs and CAs[19,20,62,70,71] and this qualitative study explored how culture, race, and health status contributed to those disparities. Diverse views were ascertained based on study findings[20] and PT’s experiences. Color blindness was common among CA PTs, whereas AA PTs acknowledged how race and other issues impacting health lowered the potential for AAwS to actively engage in rehabilitation, receive equitable care, and have favorable outcomes comparable to CAs. Color blindness is documented as operating in various professions and apparent when providers are CA and the patient is a racial or ethnic minority.[218-220] As found in research, invoking color blindness and although not intentional, subliminal negative attitudes and actions[220-223] are reflective of discrimination and raced-based treatment that is inequitable in physical therapy practice. Being of the CA dominate culture, providers act from a place of privilege not being able to embody experiences of someone different and lack understanding how those differences often attribute to health. AA PTs however, recognized the interplay of race with socioeconomic status, education and cultural habits impacting health. In CRT, this interplay is intersectionality and accounts for another tenet, anti-essentialism, which is defining a group by more than one characteristic. The AAs appeared to understand how race influences health behaviors and therefore, acknowledged and addressed it by their interactions with AAwS.

Issues of justice and equality were interconnected to other themes. No subgroup

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was identified by extrinsic characteristics except AAs with moderate stroke:

> [b]lack patients were younger, were more likely to be female and under Medicaid coverage, and had more hypertension and obesity with body mass index greater than or equal to 30[20(p1717)]

Responses to multiple questions referred back to this description of AAs describing patient-related and not PT-centered rationales that impacted clinical reasoning processes (patient social health attributes). For example, when families were unavailable for education due to employment, and involvement requires presence, an alternate time for education was not suggested (family capacity). Patients were not treated based on clinical need, but rather staffing, payor source and health care policy (systematic health care limitations). Therefore, if AA and on Medicaid, chances are therapy was not provided in minutes equitable to other insured patients (therapy intensity). Despite PTs mentioning uninsured [Black] patients were kept longer to get their needs met, the underlying implication was that less aggressive therapy and less time were spent due to comorbidities such as obesity, rendering some activities unsafe for PTs to perform alone. African Americans also had less time in therapy because they were having tests performed related to comorbidities. In the moderate stroke group, AAs were described as being less independent or ambulatory prior to their stroke. There were no responses encouraging physical activity of AAwS derived from past health practices and cultural habits; however, AA and CA PTs within a FG stated PTs needed to do a better job demonstrating care and concern, motivating AAwS, educating how cultural habits impact health, and integrating therapy into their lifestyle. These actions reflect health outcome investment and patient social health attributes both containing cultural components.

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Prejudice and stereotyping are racial biases, leading to discrimination.[41] Skin color activates implicit biases and stereotypical thoughts, corresponding to social categorization of people rooted in held beliefs and assumptions. This is particularly true for AAs based on slavery in this country. Beliefs and assumptions are nonclinical factors, which influence the medical encounter affecting clinical decision-making processes that may contribute to health disparities between AAs and CAs.[39,64,73] Health care professions emphasize providers be properly trained and demonstrate cultural competency and ethnic sensitivity to effectively diagnose and treat AAs,[82-84] as well as acknowledge their own cultural biases that may lead to misdiagnosis.[83,84] Physicians have more negative implicit attitudes and stereotypical thoughts towards AAs, as being noncompliant patients and less likely to participate in rehabilitation therapy.[39,100,126] Perhaps these findings are relevant to the patient-PT relationship. Racial bias on the part of the provider[83] and cultural mistrust by AA patients in a CA-dominated health care system[27,137] may influence rehabilitation outcomes.[27,28] Positive health behavior change for AAwS may be compromised when PTs lack understanding of cultural variables present in the lives of AAwS, which may bear significantly on their capacity to maintain recommended therapy strategies.

Several factors contributed to possible study limitations. Transcript reviews indicated long pauses before answers, perhaps indicating PTs not understanding questions or having a response, and or feeling uncomfortable expressing opinions. Therapy definitions, data, and results had to be explained. Participants may have formed opinions before fully understanding the study data and results. Last, information generated may have been skewed by race-based perceptions (e.g. color blindness) of FG

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participants. One group was all CA, the other a mixture of AA (two) and CA PTs.

In conclusion, diverse and complex issues were revealed describing how culture, race, and health status are related to stroke care and outcome disparities based on quantitative study findings[20] and PTs' experiences. Culture sets the precedence for how individuals perceive, receive, and adhere to health care information. Cultural traits have the potential to influence health behaviors. It is important that if there is cultural discordance and no shared lived experiences; PTs should demonstrate understanding and sensitivity relevant to patients' culture. The same should be demonstrated when race is a factor; however, if ignored, understanding how race and its inter-related components influence health will not be considered, thus possibly impacting the patient-PT relationship, treatment, and outcomes. Future studies should investigate how physical therapy care processes can accommodate culture, race, and health status to eliminate stroke rehabilitation care and disparities.

Mrs Greene, Dr Bryan and Dr Fritz provided concept and idea. Mrs Greene, Dr Bryan, and Dr Friedman provided research design and data analysis. Dr Bryan, Dr Friedman, and Dr Fritz provided manuscript review. Dr Durstine and Dr Newman-Norlund provided consultation. Mrs Greene acknowledges Otis L. Owens, Ph.D.(c), MPH, research assistant, Donna Chisolm, PT, MS, Joni Dunmyer, MS, and Robert Campbell, Ph.D. for their contributions to study.

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Table 4.2 Physical Therapists Characteristics

Participant No.	Age (y)	Sex	Race	Highest Professional Degree	Stroke Experience IRF[a] (y)	Cultural Competency Education (CCE)	CCE Contact Time
1	56	Female	Caucasian	Bachelor	24	Hospital teaching conferences	Time not reported
2	30	Female	Caucasian	DPT	4.5	Module(s) or class session(s) of physical therapy program course	Does not remember
3	45	Female	Caucasian	Bachelor	22.5	Does not remember	NA
4	53	Male	Caucasian	Bachelor	12	Does not remember	NA
5	58	Male	Caucasian	Bachelor	7	Employer inservice	Time not reported
6	28	Female	Caucasian	DPT	2	Module(s) or class session(s) of physical therapy program course	15 hours
7	48	Female	Caucasian	Bachelor	1	Does not remember	NA
8	26	Female	African American	DPT	1.5	Semester course of physical therapy program	12 weeks
9	62	Female	Caucasian	t-DPT[b]	23	Semester course of physical therapy program	6 weeks
10	56	Female	African American	Bachelor	14	Module(s) or class session(s) of physical therapy program course	Time not reported

[a]IRF=inpatient rehabilitation facility
[b]t-DPT=Transitional doctorate

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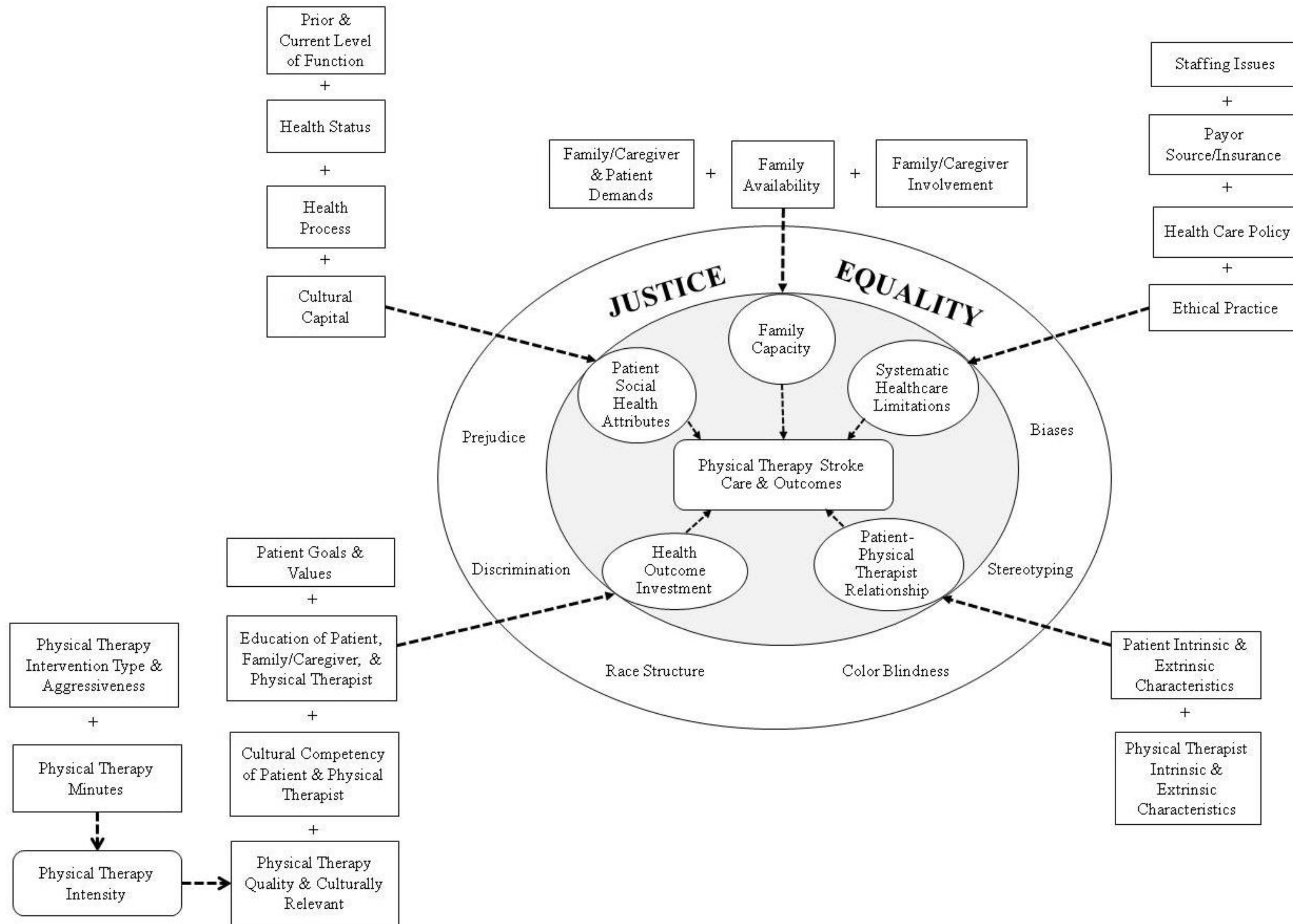

Figure 4.2 Themes derived from the perspectives of physical therapists

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CHAPTER 5

DISCUSSION AND CONCLUSION

5.1 DISCUSSION

Distorted perceptions of race and culture and the lack of knowing and understanding cultural habits in the patient-PT relationship may contribute to the disparities in stroke rehabilitation care and outcomes for AAwS. Horn et al suggested that future studies investigate how a patient's health status or race is associated with the therapy provider's choice of activities and treatment interventions within activities for AAs and CAs.[20] The purpose of this study was to explore the perspectives of: (1) AAwS regarding the ways in which culture and race may have influenced their experiences during inpatient rehabilitation, and (2) PTs regarding how culture, race, and health status (the latter two evidenced in literature)[20] contribute to the disparities in rehabilitation care and outcomes between AAs and CAs with stroke.

Perspectives of AAwS. Data analysis revealed six themes: (1) self-acknowledgement, (2) shift in barriers to optimal health, (3) health cultured inferiority or subordination, (4) health outcome investment with a subtheme, culturally-relevant and functional activities, (5) issues of trust, and (6) race role interaction that addressed the perceptions of AAwS regarding the ways in which culture and race played a role in their inpatient rehabilitation experiences. Four AAwS had a CA PT as their primary therapist. With CA PTs, when trust was not established in the relationship or the PT was perceived as prejudice, racist, or indifferent towards the participant, race was an issue and treatment

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was different for AAs compared to CAs. Treatment was different in time spent, and quality (type and aggressiveness) or how it was given by the therapist. Overall, these findings are similar to those found in the Horn et al study.[20] One participant could not compare treatment, because stroke severity did not warrant the same therapy as other CAs with stroke. Diverse views were given denoting how culture and race impacted rehabilitation outcomes. Four of five AAwS expressed outcomes were related to patient characteristics (attitude, motivation, and health practices) and three AAwS who had CA PTs and received differential care, stated that CA PTs spent more time and performed better quality therapy with CAs with stroke. The participant who had an AA PT was impressed how the PT made an effort to know her, provided culturally-relevant therapy, and felt she received equitable care compared to CAs based on her stroke impairments.

Perspectives of PTs. Data analysis revealed six themes: (1) justice and equality, (2) family capacity, (3) patient-PT relationship, (4) health outcome investment, with a subtheme of physical therapy intensity, (5) systematic healthcare limitations, and (6) patient social health attributes that addressed PTs' perspectives of how culture, race, and health status impacted the choice of activities and treatment interventions within activities and the time associated with activities and interventions, contributing to racialized stroke rehabilitation care. Caucasian American PTs invoked color blindness whereas AA PTs embraced race and cultural habits integrating them in therapies. Prejudice, bias, race and racism, stereotyping, and discrimination were other components of the justice and equality theme that were elements of: (1) family capacity (availability - employment as racial economic stratification), (2) patient-PT relationship (individual level racism or discrimination via attitudes and behavior), (3) health outcome investment

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(racialized treatment based on time, type, and quality), (4) systematic health care limitations (institutionalized racism), and (5) patient social health attributes (stereotyping – therapies based on prior and current levels of function and health practices without consideration of cultural capital).

5.2 LIMITATIONS

Limited participation from AAwS was due mainly to recruitment fallacies. Social workers and CMs from seven IRFs agreed to distribute packets to AAwS who met eligibility and were being discharged from the inpatient rehabilitation unit or attending stroke support meetings. Rehabilitation directors/managers and CMs assured me that recruitment packets were being distributed; however, after internal investigation and by asking AA participants if they had received recruitment packets (four from the same facility did not), it was made clear that the recruitment packets were not being distributed. Individuals from only two IRFs stated that databases were searched for eligible AAs (diagnosed with stroke and discharged from the IRF after January 1, 2012) and recruitment packets were mailed. One AA participant showed me the recruitment packet received. I was unable to make contact with all persons in charge of stroke support groups affiliated with the IRFs to solicit AA participants. I was not granted permission to attend stroke support group meetings and told it would not be of benefit to attend at one facility because at the current time, there were no AAwS attending or I was told that the person in charge of the stroke group would distribute recruitment materials. Also, I had 12 recruitment packets returned from AME churches because of no mail receptacle. I asked for the correct addresses via a phone call and an email to the AME state office, but neither inquiry produced a response. Limited participation from PTs was due to

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eligibility, disinterest, and the time commitment to meet after work on a weekday. The population from which to draw a sample was not large to start. Statistics indicated that at the nine IRFs, there were 34 PTs who self-report as White and one as Black (Byron Kirby, Program Manager, Office of Research & Statistics, S.C. Budget and Control Board, Email Conversation, May 11, 2012).

Other limitations were related to the interviews. Participants may have not understood the questions. Repeated reading and coding of the transcripts demonstrated that questions were answered based on the perception of what was heard or read and or experiences encountered. There were long pauses for one AA participant with stroke and during the FGs, particularly longer for the all CA FG. For the AA participant, it was later discovered that he had language and comprehension deficits, despite being a great conversationalist. The PTs may not have had a response or did not feel comfortable expressing their views. Definitions of motor control versus motor learning and community mobility as well as research data in the study had to be explained. Physical therapists asked what motor control and or motor learning is and I had to read them a definition. I had to explain community mobility based on the information in the table for physical therapy variables because in the table for occupational therapy variables, the term community integration was used.[20] Physical therapists did not understand *p* value and indicators of significance in the table physical therapy variables.[20] Therefore, PTs may have formed opinions before fully understanding the study data and results. Last, the information generated may have been skewed by the race-based perceptions (e.g. color blindness) of FG participants. One group was all CA PTs and the second, consisted of two AAs and a CA.

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5.3 CONCLUSIONS

The diversity of these themes demonstrates the complexities involved in providing equitable care related to culture, race, and health status. Also, culture and race of the patient and PT are characteristics that factor into the patient-PT relationship or therapeutic alliance in physical therapy practice, from the perspectives of AAwS and AA PTs. For CA PTs however, race is not considered an issue in therapy contributing to differential care and subsequent disparities in stroke care and outcomes, but other patient characteristics (socioeconomic status, insurance, and education level) contribute to disparities. Caucasian American PTs did not acknowledge cultural habits unless they were impacting treatment. African American PTs acknowledged race and cultural habits, understanding that those factors impacted health and accommodated for them during therapy. Future qualitative studies should investigate how physical therapy practice and the patient-PT relationship or therapeutic alliance can accommodate the factors of culture, race, and health status to eliminate stroke rehabilitation care and outcome disparities between AAs and CAs by interviewing and observing individuals with stroke and their primary PT.

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APPENDIX A - AFRICAN AMERICANS WITH STROKE FLIER

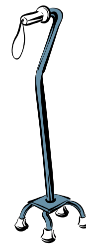
Did you have a stroke and follow-up care at an inpatient rehabilitation unit after January 1, 2012?

If you are an African American/Black, above the age of 21, had one (1) stroke, and would like to discuss your physical therapy stroke rehabilitation experience,

Please Contact

Jennifaye V. Greene
Physical Therapist
University of South Carolina
Doctoral Student
phone: 843.364.5089 email: greenejv@email.sc.edu
The group discussion will last no longer than 90 minutes.

$25.00 cash given for participation



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APPENDIX B - AFRICAN AMERICANS WITH STROKE
INVITATION LETTER TO PARTICIPATE

Arnold School of Public
Health Department of Exercise Science
Physical Therapy Program
Rehabilitation Lab

Summer 2012

Dear Madam and Sir:

You are invited to participate in a research study about stroke health disparities for the fulfillment of my dissertation requirements. It will require that you participate in a one-time group discussion (3 persons minimum per group) lasting 60-90 minutes to answer nine (9) questions about your inpatient rehabilitation physical therapy experience at **IRF**. Before the group discussion, you will also have to complete a short survey about yourself. Someone will be available to assist you if needed to complete the survey. The group discussion will be held at **IRF** or a location convenient for you. You will receive $25.00 cash for your participation.

If you are interested, please discuss with your family or other friends who have had a stroke about a date and time convenient for you to participate as a group, and then contact me. Please see the contact information below.

I appreciate your contribution to assist me in my education by participating in this study.

Warm Regards,

Jennifaye V. Greene, Ph.D.(c)
Arnold School of Public Health
Department of Exercise Science
Physical Therapy Program
Confidential Voice Mail: 843.364.5089
Email: greenejv@email.sc.edu

Mailing Address:
1635 Mulberry Street
Charleston, SC 29407

941 Assembly Street ◊ Public Health Research Building ◊ 3rd Floor, Room 308A ◊ Columbia, SC 29208

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APPENDIX C - PHYSICAL THERAPIST FLIER

Are you a full-time (32 hours) Physical Therapist employed on the inpatient rehabilitation unit & treating individuals with stroke for more than 1 year?

If you would like to discuss rehabilitation care extended to African Americans and Caucasian Americans with stroke that is reported in the literature,

Please Contact

Jennifaye V. Greene
Physical Therapist
University of South Carolina
Doctoral Student
phone: 843.364.5089 email: greenejv@email.sc.edu

The group discussion will last no longer than 90 minutes.

$25.00 cash given for participation

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APPENDIX D - PHYSICAL THERAPIST INVITATION LETTER TO PARTICIPATE

Arnold School of Public
Health Department of Exercise Science
Physical Therapy Program
Rehabilitation Lab

Summer 2012

Dear Physical Therapist:

You are invited to participate in a research study about stroke health disparities for the fulfillment of my dissertation requirements. It will require that you read the attached article and participate in a one-time focus group discussion (3 person minimum per group) lasting 60-90 minutes to answer six (6) questions about the article and based on your experiences as a physical therapist. Preceding the focus group discussion, you will also have to complete a short demographic survey. The focus group discussion will be held at **IRF** or at a location convenient for you. You will receive $25.00 cash for your participation. Refreshments will be served.

If you are interested, please discuss with your colleagues about a date and time convenient for you to participate as a group, and then contact me. Please see the contact information below.

I appreciate your contribution to evidence-based practice in physical therapy by participating in this study.

Warm Regards,

Jennifaye V. Greene, Ph.D.(c)
Arnold School of Public Health
Department of Exercise Science
Physical Therapy Program
Confidential Voice Mail: 843.364.5089
Email: greenejv@email.sc.edu

Mailing Address:
1635 Mulberry Street
Charleston, SC 29407

941 Assembly Street ◊ Public Health Research Building ◊ 3rd Floor, Room 308A ◊ Columbia, SC 29208

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APPENDIX E - AFRICAN AMERICANS WITH STROKE SURVEY

1. **Stroke Survivor Information**
   Participant Identity #: ______________________________
   Phone Number: __________________________ ☐ Home ☐ Cell
   Best time to reach you: ____________________________ ☐ am ☐ pm

2. **Gender** ☐ Male ☐ Female

3. **Age** __ __

4. **Who is your primary Caregiver (the person who takes care of you)? Read list if applicable.**
   ☐ Self
   ☐ Husband ☐ Wife ☐ Sister ☐ Brother ☐ Son ☐ Daughter
   ☐ Mother ☐ Father ☐ Companion ☐ Partner ☐ Friend
   ☐ Other Relative – Relation ___________________________________

5. **Where were you born?** _______________________________________

6. **Where were you raised?** _______________________________________

7. **What is your highest level of education? Read list if applicable.**
   1 Elementary School
   2 Some High School
   3 Completed High School (Graduated or Completed GED)
   4 Some College or Technical School
   5 College Graduate (2-year Technical School or 4-year College)
   6 Some Graduate Level Education
   7 Completed Graduate School

8. **Are you currently employed?** ☐ Yes ☐ No
   If **Yes**, Employer: ____

9. **When did you have a stroke?** ______________ ________ ________
   Month **Date** **Year**

10. **Which side of your body was affected by the stroke?**
    ☐ Left ☐ Right

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11. Do you know where in your brain the stroke was located?

☐ Yes Location: ____________________

☐ No

12. How would you describe your general health right now?

Please circle the one most appropriate answer. **Read list if applicable.**

1 Excellent
2 Very Good
3 Good
4 Fair
5 Poor

The **primary physical therapist** refers to the person who does the initial evaluation (when you first came to inpatient rehabilitation) and discharge evaluation (last evaluation before going home or to another facility) and updates the status of your progress and weekly goals. You may or may not have had the same **physical therapist** to provide all of your physical therapy sessions.

13. Do you remember who your primary physical therapist was on inpatient rehabilitation?

☐ **Yes** I remember **write** first name only if you remember ________________

☐ **No** I do not remember If **No,** please proceed to question #16.

14. Was your physical therapist Hispanic, Latino/a or Spanish origin?

☐ **Yes** Hispanic, Latino/a or Spanish

☐ Do not know If you do not know, please proceed to question #15.

☐ **No** If No, please proceed to question #15.

15. To what racial group does your physical therapist belong?

☐ Black or African American

☐ White or Caucasian American

☐ Asian

☐ Native Hawaiian or other Pacific Islander

☐ American Indian or Alaskan Native

☐ Other __________________________________ (please write racial group)

☐ Do not know

16. How would you rate your overall satisfaction with your physical therapy inpatient rehabilitation experience?

Please circle the one most appropriate answer. **Read list if applicable.**

1 Excellent
2 Very Good
3 Good
4 Fair
5 Poor

End of Survey

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APPENDIX F - PHYSICAL THERAPIST SURVEY

1. **Physical Therapist Information**
   Participant Identity #: ______________________________
   Phone Number: ___________________________ ☐ Home ☐ Cell
   Best time to reach you: _____________________________ ☐ am ☐ pm

2. **Gender** ☐ Male ☐ Female

3. **Age __ __**

4. **Are you Hispanic, Latino/a or Spanish origin?**
   ☐ Yes Hispanic, Latino/a or Spanish
   ☐ No **If No, please proceed to Question #5**

5. **To what racial group do you belong?**
   ☐ Black or African American
   ☐ White or Caucasian American
   ☐ Asian
   ☐ Native Hawaiian or other Pacific Islander
   ☐ American Indian or Alaskan Native
   ☐ Other ______________________________________ (please write racial group)

6. **Highest professional degree in physical therapy:**
   ☐ Certificate
   ☐ Bachelor
   ☐ Master
   ☐ Doctorate
   ☐ Transitional-doctorate
   ☐ Doctorate of Philosophy

7. **Current employer: ____**

8. **Are you board certified in neurology by the American Physical Therapy Association?**
   ☐ Yes ☐ No

9. **Did you complete a neurologic residency by the American Physical Therapy Association?**
   ☐ Yes ☐ No

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10. How many years have you worked as a full-time (32 hours) employee on an inpatient rehabilitation unit treating individuals with stroke?

____

Culture is the sum of intergenerationally transmitted and cross-culturally acquired lifestyle ways, behavior patterns, and products of a people that include their language, music, arts and artifacts, beliefs, interpersonal styles, values, habits, history, eating preferences, customs, and social rules. Furthermore, culture can be characterized by people who share a common geographic place, common experiences, and a specific time in history.

11. What best describes how you were taught about cultural competency?

☐ A semester course

If a semester course, how many weeks? ___________

☐ A module or class session within a course

If a module or class session within a course, how many contact hours? __________

☐ Employee inservice

☐ Continuing education course

☐ Conference presentation

☐ Do not remember

End of Survey

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APPENDIX G - INTERVIEW GUIDE FOR AFRICAN AMERICANS WITH STROKE

1. Issue Statement

When groups of people live together, they develop a way of life to meet their needs, known as culture.

***Culture** is your personal* lifestyle and behavior patterns including your religion, language, music, artwork, beliefs, values, daily habits, history, food and eating preferences, customs, and social rules

Culture refers to people who share a common geographic place (Southern), common experiences, and a specific time in history (for example, slavery or Civil Rights Era)

*For you, **culture** is how you live as an African American or a Black person.*

Group Question: *What are some unique things about how you live as an African American or a Black person?*

PROBES:

- **a.** Tell me about your life at home.
- **b.** Tell me about your past or current work life.
- **c.** Tell me what you do for leisure or fun.
- **d.** What are your beliefs about health?
- **e.** What do you value about your health?
- **f.** Tell me about your health practices or being healthy.

2. Issue Statement

In order to develop specific goals and treatment for you, your physical therapist may have asked you about how you live as an African American or a Black person.

Group Question: *What were some of the things that your physical therapist asked you about how you live as an African American or a Black person?*

PROBES:

- **a.** What did your physical therapist ask about your life at home?
- **b.** What did your physical therapist ask about your work situation?
- **c.** What did your physical therapist ask about your leisure or fun activities?

3. Issue Statement

Many of us are familiar with the saying, "when you know better, you do better".

Group Question: *How did your physical therapist get to know you better?*

4. Issue Statement

Many of us are familiar with the saying, "practice makes perfect".

Group Question: *What were some of the treatment activities that you practice with your physical therapist that related to how you live as an African American or a Black person?*

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PROBES:

- **a.** What did you practice in physical therapy related to your life at home?
- **b.** What did you practice in physical therapy related to your work?
- **c.** What did you practice in physical therapy related to your leisure activity or activities?

Group Question: *What were some of the treatment activities that you **did not** practice with your physical therapist that you realized were related to how you live as an African American or a Black person?*

PROBES: What did you need to practice in physical therapy that you **did not** relate to:

- **a.** your life at home?
- **b.** your work?
- **c.** your leisure or fun activities?

5. Issue Statement

In the field of healthcare, researchers have stated that a lack of trust between the patient and the healthcare provider is a factor to rehabilitation success.

Group Question: *Describe situations if any, that a lack of trust between you and your physical therapist may have played a role during inpatient rehabilitation.*

6. Issue Statement

In the field of healthcare, researchers have stated that a patient's race is a factor to rehabilitation success.

Group Question 6a: *What are any ways you believe that being the same race as your physical therapist may have played a role during inpatient rehabilitation.* **Omit if PTs were not of same race. Refer to demographic surveys.**

Group Question 6b: *What are any ways you believe that being of a different race than your physical therapist may have played a role during inpatient rehabilitation.*

7. Issue Statement

In healthcare, researchers have argued that African Americans or Blacks may have been provided treatment differently compared to other people.

Group Question: *If so, how was your physical therapy treatment different compared to other people who had a stroke?*

8. Issue Statement

In healthcare, researchers define an outcome as the end result of how you are doing after rehabilitation is over. Outcomes are usually measured using a number. A higher number indicates a better outcome. Research indicates that overall, African Americans or Blacks with stroke are discharged with lower rehabilitation outcomes than Caucasian Americans or Whites with stroke.

Group Question: *Why do you think stroke rehabilitation outcomes are lower for African Americans or Blacks with stroke than Caucasian American or Whites with stroke?*

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9. Group Question

Is there any other information about your inpatient rehabilitation physical therapy experiences that you think would be important for me to know that I did not ask about?

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APPENDIX H - FOCUS GROUP INTERVIEW GUIDE FOR PHYSICAL THERAPISTS

1. Issue Statement

For patients with severe stroke, African Americans or Blacks were less sick and had higher admission total motor and cognitive FIM scores; however, there were some differences in rehabilitation care, some of those differences significant. The questions refer to activities and interventions within activities that indicated statistically significant differences.

Group Question:

Why do you think

a. *Overall, African Americans or Blacks had more patient education?*
b. *Overall, African Americans or Blacks had more formal assessment time?*
c. *For* ***interventions within activities****, Caucasian Americans or Whites had more balance training within community mobility?*
d. *For* ***interventions within activities****, Caucasian Americans or Whites had more family caregiver education within gait?*
e. *For* ***activities****, African Americans or Blacks had more wheelchair mobility?*
f. *For* ***interventions within activities****, African Americans or Blacks had more motor control within prefunctional activities? define motor control if needed* **"targeting impairments in the musculoskeletal system & encouraging purposeful mov't & postural adjustment by selective allocation of mm across joint segments" (Jette[5])**

2. Issue Statement

Caucasian American or White patients "with moderate stroke were not sicker than black patients with moderate stroke, but still white patients received more care" (Horn, 2010, p. 1719). *The questions refer to activities and interventions within activities that indicated statistically significant differences.*

Group Question:

Why do you think:

a. *For* ***activities****, Caucasian Americans or Whites had more transfer training and sit to stand exercises?*
b. *For* ***interventions within activities****, Caucasian Americans or Whites had more perceptual training within transfers?*
c. *For* ***activities****, Caucasian Americans or Whites had more community mobility?*
d. *For* ***interventions within activities****, Caucasian Americans or Whites had more motor learning within community mobility? define motor learning if needed* ***"targeting impairments in the neuromuscular system & providing practice or an experience leading to a change in the capability of producing a skilled action" (Jette[5])***

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e. *For **interventions within activities**, Caucasian Americans or Whites had more family caregiver education within gait?*
f. *For **activities**, African Americans or Blacks had more wheelchair mobility training?*
g. *For **interventions within activities**, African Americans or Blacks had more prefunction motor control?*
h. *For **interventions within activities**, African Americans or Blacks had more sitting motor control?*

3. Issue Statement

*For patients with moderate and severe stroke, overall, Caucasian American or White patients received more rehabilitation care (**therapy**: activities & interventions within activities & **nontherapy**: medical & nursing). Also, "racial differences were found with white patients usually getting more intense therapy (number of minutes of therapy) than black patients, a finding that supports pasts and more recent reports"* (Horn, 2010, p. 1719). *The differences in rehabilitation care appear **not** to be related to health status. Horn proposed that a study be done to determine the clinical reasoning processes that health care practitioners use when selecting different processes of care (activities and interventions) for Caucasian Americans or Whites and African Americans or Blacks.*

Group Question: *What is the clinical reasoning process(es) that you have used or observed to determine the difference in choice of activities and interventions for Caucasian Americans or Whites versus African Americans or Blacks.*

4. Issue Statement

Mainly in the moderate stroke group, "Blacks were younger, had a higher percentage of women, were less independent or ambulatory prior to their stroke, and were more likely to be on Medicaid, suggesting different socioeconomic backgrounds compared to white patients" (Horn, 2010, p.1719).

Group Question: *What are your opinions why these characteristics of African Americans or Blacks may have contributed to the "clinicians' choice of treatments by race"* (Horn, 2010, p.1712).

5. Issue Statement

***Median session duration** "represents a specific predetermined time interval that each facility provides to their patients as a policy" per Dr Horn via email conversation which is the Medicare standard of 3 hours of OT, PT, and ST per day. Overall, African American or Blacks in the moderate and severe stroke group had statistically significant longer (minutes) **median session durations** compared to Caucasian Americans or Whites. But, Whites overall had higher minutes/per day in activities and interventions within activities.*

Group Question: *Why do you think* Caucasian Americans or Whites *had more minutes of activities and interventions within activities even though African Americans or Blacks had longer median session durations?*

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6. Issue Statement

Research indicates that overall, stroke rehabilitation outcomes are lower for African Americans or Blacks with stroke.

Group Question: *Why do you think stroke rehabilitation outcomes are lower for African Americans or Blacks with stroke?*

7. Group Question

How do you address the cultural habits of your patients in physical therapy practice?

8. Group Question

Is there any other information that you think would be important for me to know that I did not ask about?

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APPENDIX I - POSTINTERVIEW REFLECTION FORM

I. <u>Lingering Questions</u>

A. From your thoughts and reflections:
B. From notes:

II. <u>Issues for Exploration Next Time</u>

A. From your reflections:
B. From notes:

III. <u>Contextual Notes</u>

A. Where did the interview occur?
 1. Anything significant about the location?
B. Under what conditions did the interview take place?
C. How did the participants react to the questions?
D. How well do you think you did asking questions? What issues did you encounter?
E. How was your rapport with the participants?

IV. <u>Notes on the Interview Process</u>

A. How do you feel about the quality of the information?
*B. Did you find out what you really wanted to find out in the interview?*__________
 If not, what was the problem?
C. What did the participants say that was confusing to you?
D. Did any information contradict what was said in previous FG or what was in the literature?

V. <u>All About You</u>

A. What was your state of mind before, during and after the interview?
B. Is there anything of significance that should be noted about you and your interactions during the interview?
C. What previous assumptions have been influenced by the data collected today?(reflective subjectivity)

VI. <u>Major Themes Mentioned/Discussed</u>

VII. <u>Additional Journal Entries</u>

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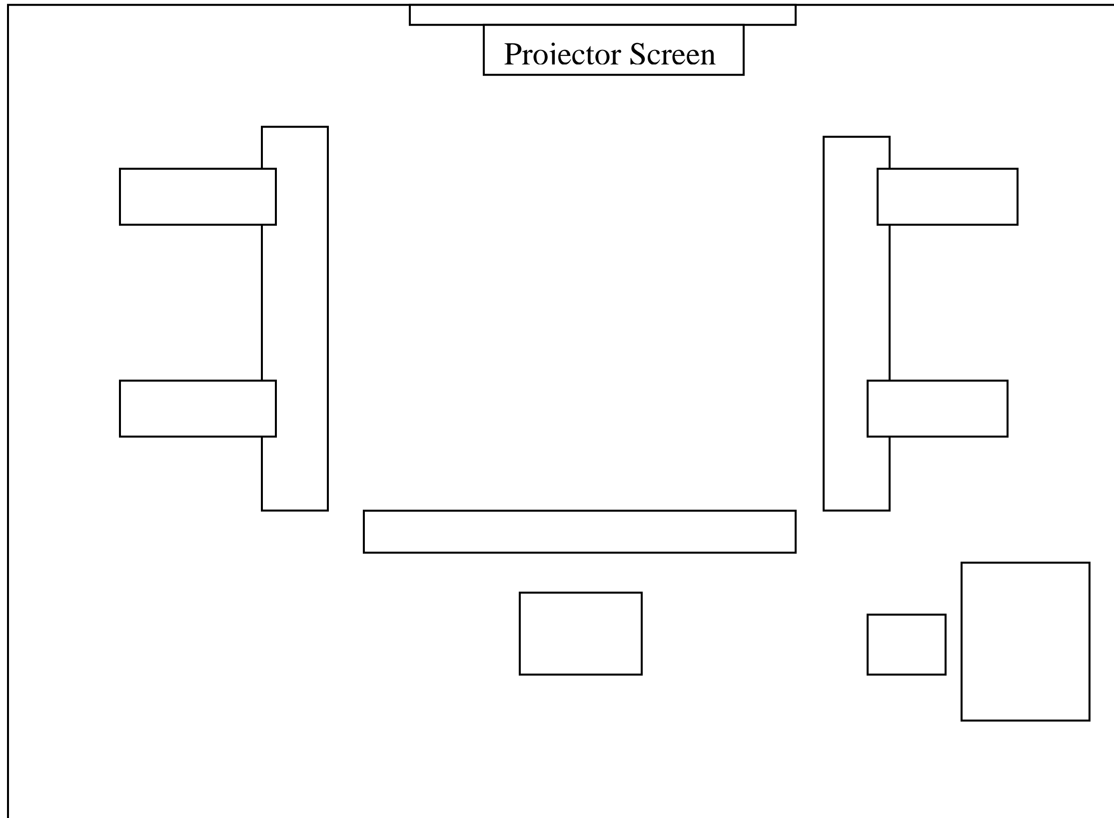
APPENDIX J - NOTE TAKER FORM

Seating Chart: Indicate participants by their given identifier number (P#);
M= moderator; N=note taker



Question # or key words	**Responses**	**Observations**
Question 1		
Question 2		
Question 3		
Question 4		
Question 5		
Question 6		
Question 7		
Question 8		
Question 9		

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APPENDIX K - JOURNAL ENTRY

Journal Dec 15, 2012
4:30 pm

Group Question:
For patients with severe stroke, if Blacks were less sick and a higher admission total motor and cognitive FIM scores, why do you think, overall, Blacks had more patient education? This is question 1A

4-1: Ok, part of the reason I feel Blacks had more education, even though they were less sick and higher admission total motor and cognitive FIM scores, is with more severe strokes you're going to have more involvement cognitively and um…physically. And so you're constantly educating the patient and the family on the release process, what they can do to prevent it um…and just overall general education for the patient.

I think 4.1 confusing stroke severity category with being sicker in terms of cognitive status. The issue statement says that Blacks had a higher Cognitive FIM score so even in stroke severity group cognition was not a problem for blacks. Blacks may have qualified for stroke severity category because of motor impairment.

Same for 6-1 lines 103-105
6-1: 6-1 I uh, agree with uh the later statement that was just made. It is a whole lot easier to educate uhm that patient population when they are be-better able to understand. You really have to do a lot of the creative type of things to-to educate when they're not cognitively aware. So, I agree with what she said.

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APPENDIX L - MEMBER CHECKING LETTER

Department of Exercise ♦ Science Physical Therapy Program ♦ Rehabilitation Lab
941 Assembly Street ◊ Public Health Research Building ◊ 3rd Floor, Room 308A ◊
Columbia, SC 29208

AAwS
Address
City, SC zip code

December 4, 2012

Dear AAwS,
I hope all is well with you during this holiday season. I would appreciate if you would review this transcript. This is an opportunity for you to reread the questions and add, delete, or correct information so that the information conveys what you wanted to say.

If writing the information will be difficult, call me and we can discuss over the phone. There are a few things I did not fully understand.
Lines 792 & 794 – You do not think you spent as much time as you should have doing what?
Line 841 – says "I think it did" which refers back to question from lines 823-825 about a patient's race being a factor to rehabilitation success. If you think race did play a factor in your inpatient rehabilitation physical therapy services, please elaborate.

Again, please call me if you are unable to write or get someone else to write in detail what you want to say. Please return the transcript in the envelope provided after you have reviewed the information and or called me to discuss the information.

Thank you for your support of my research. Your opinions deserve to be heard!
Warm Regards,

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Physical Therapy Program
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APPENDIX M - PILOT STUDY

A pilot study was conducted to determine the feasibility of recruitment and whether FG questions were appropriate to generate information that answered the RQs. Major issues became apparent with recruitment and data collection, specifically content and delivery of FG issue statements and questions.

Recruitment. The time required to complete multiple external IRB application processes and obtain study approval as well as receive responses from IRFs regarding study participation impacted recruitment. Of the nine IRFs solicited to participate, five free standing and two hospital-based facilities required a separate IRB application process. One hospital-based IRF and another free standing IRF required hospital administration approval, and the latter choose not to participate. The nine IRFs had 35 potential PTs to participate in the pilot and research study (Byron Kirby, Program Manager, Office of Research & Statistics, S.C. Budget and Control Board, Email Conversation, May 11, 2012). The following reasons effected recruitment: (1) for those PTs who met eligibility, some opted not to participate, (2) PT ineligibility due to employment status or length of time working in inpatient rehabilitation, (3) if hospital administration said, “no” to participation, I was unable to secure the names of staff PTs to invite them to participate outside of the facility setting, and (4) inability to get recruitment fliers to eligible AAs prior to discharge from the IRFs. Four PTs and three AAwS from one facility participated in the pilot study.

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Data Collection. The second major issue revealed was regarding data collection. Surveys, interview questions, moderator and RA notes, postinterview reflection notes, and journal entries served as methods for data collection. Primary data however, were derived from interview questions and subsequent probe questions that were added as needed to generate information based on initial responses or if the topic question was not addressed. I was made aware of three issues by engaging in FG debriefings with the RA, listening to the digital recordings and adding comments to the RA notes, completing the postinterview reflection forms, and reading the transcriptions while listening to the digital recordings.

These issues were: (1) questions were not understandable, despite AAwS stating they understood them, (2) PTs did not understand information in the Horn et al article,[20] and (3) how the content and delivery of the issue statements and questions could be changed. In general, it appeared that none of the AAwS understood the definitions or statements regarding culture, trust, and racial identity. Also, probing was required, but in listening to the digital-recorder, the probe questions were not structured and my asking successive probe questions instead of one at a time may have further confused the AAwS. Notes from the RA indicated that some of the participants looked back and forth at me and the screen, repeated questions by whispering to their selves, looked confused at times, hesitated before answering questions, and stated they did not understand the question or could not remember their PT. The following changes were made to have questions easily understood and generate information relevant to the RQs.

During the phone screening process, I defined the role of the PT and ask the AAwS if they remembered their primary PT. On the survey, I asked them to write the

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first name of their primary PT and on the power point slide, I asked them to remember the name of their primary PT and answer all the questions while thinking about their interactions with that person. Specific probes were used to inquire about their life at home, past or current work and leisure activities, and health values, beliefs, and practices, or being healthy.

The issue statements entailed greater detail leading up to the question and the language of the question reflected what was previously said in the issue statement. For example, the issue statement on differential treatment towards AAs was a summary of what was in the literature instead of explaining what differential treatment is. The subsequent question asked "how were you treated by your PT?" which generated answers on a continuum of good to bad, not examples of different treatment interventions that could warrant different outcomes based on stroke impairment.

In summary, the following changes were made to the FG questions for AAwS. I along with the RA did not feel that the AAwS understood "way of living" or "race or ethnic culture" to describe culture. "Ways of living" was changed to "way of life" or "how you live" as an AA or Black. It needed to be emphasized that culture is how you live as an AA or Black and "how you live as an AA or Black" was used consistently in questions one, two, and four. Probes were added about life at home, and the same for work and leisure for questions one, two, and four. Three separate probe questions about health beliefs, values, and practices were added to question one. The terms "racial," "racial group," or "racial identity" were omitted and the word "race" was kept as a key word for question six. In issue statement five, I changed the wording to describe cultural mistrust and removed the definition for it and racial identity in issue statement six. In

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issue statement eight, none of the participants thought rehabilitation outcomes were *better* for CAs. The authors state that rehabilitation outcomes are better for CAs[20] based on the type of intervention and a higher numerical value indicative of getting more therapy in the number of interventions and in the number of minutes devoted to those interventions.[19,20] "Better" however, was not defined formally in a quantitative or qualitative format.[20] Therefore, I explained in more detail what a higher numerical value and measuring outcomes mean in the issue statement and used the wording "rehabilitation outcomes are lower" in question eight.

Refer to Table M.1 for original issue statements and questions and subsequent changes in Appendix E. For the delivery of questions, AAwS suggested having the issue statement on the power point slide. Last, I have decided to put one question or probe per slide because AAwS would read ahead and answer the probe to the original question.

The PTs commented that they did understand all of the questions asked. One PT expressed not understanding the term "sick" or "sicker" used in the issue statements, and thereafter, other PTs agreed. It however, was also apparent that the PTs did not seem to understand the difference between moderate and severe stroke, health status of individuals within each group and the relationship between race, health status, and therapy and nontherapy ancillary care provided to individuals. Despite the fact whether in the moderate or severe group or health status, significant differences in therapy and nontherapy care variables indicated overall that CAs received more care. Therapists did not refer back to the findings of the article, particularly for stroke severity (moderate or severe group) and health status (level of sickness) in their answers. In light of these findings, I added definitions of "sicker," and "moderate and severe group" as well as

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highlighted within each slide whether AAs of CAs were sicker or if there was no difference in health status between them. Questions were prefaced if indicated, with "activities" or "intervention within activities" when asked. The word "different' was inadvertently omitted from question four between the words suggesting and socioeconomic; however, it did not appear to confuse the participants. They continued to answer the question along the lines of previous questions, stating that treatment was not provided based on race, but on other factors. The PTs were given an option to write their answers for question four, but agreed to discuss their opinions. The PTs indicated that the issue statement should remain on the slide as each question is being displayed and asked. Refer to Table M.2 for original issue statements and questions and subsequent changes in Appendix F.

The purpose of the pilot study was to determine the thoroughness of qualitative methodology needed to conduct future research. Recruitment was an issue. Anticipating four to 12[187,189,215] participants per FG and having three to four FGs[179,187] was not feasible as recommended in the literature. Therefore, revising the questions to get meaningful and insightful descriptions of the experiences and opinions of AAwS and PTs is vital to qualitative inquiry, because it lends to generating a plethora of information capable of answering the RQs by an atypical number of participants per FG (three) and the number of FGs. Revisiting the data multiple times via discussion with the RA, listening to the digital recordings, writing in a journal, and rereading the transcripts created many opportunities to find flaws in the content of issue statements, questions, and probes and question delivery, as well as recognize misunderstandings of the Horn et al article[20] based on responses not related to the question topics or observations of communication

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behaviors, particularly for AAwS. Developing and implementing an aggressive recruitment plan for AAwS and refining the FG issue statements and questions proved to be beneficial to conducting the research study. Qualitative methodology however, allows for flexibility in data collection to accommodate the variability in conditions related to participants and instrumentation.[149] Therefore, data analysis evolved (concept of content sufficiency and method to achieve it) to justify limitations in recruiting AAwS (5 participants).

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M.1 Original Interview Guide for African Americans with Stroke

	Issue Statement and Question
1	**Issue Statement:** *When groups of people live together, they develop ways of living to meet their needs, known as race or ethnic culture?*
	Question: What are some ways of living that is unique to your race or ethnic culture as Blacks? **PROBE:** What are your beliefs, values, and practices about health or being healthy?
2	**Issue Statement:** *In order to develop specific goals and treatment for you, your physical therapist may have asked you about your way of living.*
	Question: What were some of the things that your physical therapist asked you about how you live?
3	**Issue Statement:** *Many of us are familiar with the saying, "when you know better, you do better."*
	Question: What are some of the ways in which you think your physical therapist was able to get to know you better?
4	**Issue Statement:** *Many of us are familiar with the saying, "practice makes perfect."*
	Question: What were some of the treatment activities that you practice with your physical therapist that related to your way of living? **Question:** What were some of the treatment activities that you did not practice with your physical therapist that related to your way of living? **PROBE:** What did you need to practice that you did not?
5	**Issue Statement:** *In the field of healthcare, researchers have stated that patient cultural mistrust is a factor to rehabilitation success.* ***Cultural Mistrust*** *is the lack of trust in other people.*
	Question: What are ways you believe that cultural mistrust between you and your physical therapist may have played a role during inpatient rehabilitation?
6	**Issue Statement:** *In the field of healthcare, researchers have stated that patient racial identity is a factor to rehabilitation success.* ***Racial Identity*** *is acknowledging that you belong to a racial group.*
	Question 6a: What are ways you believe that being the same race as your physical therapist may have played a role during inpatient rehabilitation **Question 6b:** What are ways you believed the racial differences between you and your physical therapist may have played a role during inpatient rehabilitation?
7	**Issue Statement:** *In research on providing healthcare, researchers have argued that African Americans or Blacks may have been treated differently.*
	Question: How were you treated by your physical therapist?
8	**Issue Statement:** *In the field of healthcare, researchers define an outcome as the end result of how you are doing after rehabilitation is over. Research indicates that overall, Caucasian Americans or Whites with stroke experience better rehabilitation outcomes than African Americans or Blacks with stroke.*
	Question: Why do you think stroke rehabilitation outcomes are better for Caucasian Americans or Whites with stroke compared to African Americans or Blacks with stroke?
9	**No Issue Statement Question:** Is there any other information that you would be important for me to know that I did not ask about?

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M.2 Original Focus Group Interview Guide for Physical Therapists

	Issue Statement and Question
1	**Issue Statement:** *For patients with severe stroke, Blacks were less sick and had higher admission total motor and cognitive FIM scores; however, there were some differences in rehabilitation care, some of those differences significant*.* *"finding is significant"
	Questions: *Why you think* *a. Blacks received more PT education?* *b. Blacks received more PT formal assessment time?* *c. Whites received more family education within gait*?* *d. Whites received more perceptual training within transfers*?* *e. Blacks received more motor control within prefunctional activities*?* *f. Blacks received more wheelchair mobility*?*
2	**Issue Statement:** *White patients "with moderate stroke were not sicker than black patients with moderate stroke, but still white patients received more care."*[19(p1719)]
	Questions: *Why you think* a. *Whites had more intense PT community mobility activities and sit to stand exercises?* *b. Blacks received more wheelchair mobility?* *c. Blacks received more prefunction motor control?* *d. Blacks received more sitting motor control?*
3	**Issue Statement:** *For patients with moderate and severe stroke, overall, White patients received more care. Also, "racial differences were found with white patients usually getting more intense therapy than black patients, a finding that supports pasts and more recent reports."*[19(p1719)] *The differences in rehabilitation care appear not to be related to health status. Horn proposed that a study be done to determine the clinical reasoning processes that health care practitioners use when selecting different processes of care (activities and interventions) for Whites and Blacks.*
	Question: *What is the clinical reasoning process(es) that you have used or observed to determine the difference in choice of activities & interventions for Whites versus Blacks.*
4	**Issue Statement:** *Mainly in the moderate stroke group, "Blacks were younger, had a higher percentage of women, were less independent or ambulatory prior to their stroke, and were more likely to be on Medicaid, suggesting socioeconomic backgrounds compared to white patients."* [19(p1719)]
	Question: W*hy these characteristics of Blacks may have contributed to the "clinicians' choice of treatments by race."* [19(p1719)]
	Issue Statement: *Research indicates that overall, stroke rehabilitation outcomes are lower for Black stroke survivors.*
	Question: *Why do you think stroke rehabilitation outcomes are lower for Black stroke survivors?*
6	**No Issue Statement. Question:** Is there any other information that you would be important for me to know that I did not ask about?

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