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Perspectives of African Americans Diagnosed with End Stage Renal Disease and Their Perceptions Regarding Accessibility of Care

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Abstract

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MA, Central Michigan University, 2011

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Dissertation Submitted in Partial Fulfillment
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Doctor of Philosophy
Health Care Administration

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Abstract

End stage renal disease (ESRD) is the final phase of kidney disease. African Americans make up 35% of all ESRD cases, which is rising. They lead all other racial groups and are 3 times more likely to be diagnosed with ESRD. Researchers have reported quantitative results involving this population, but none have focused on their experiences. The researcher sought to capture the experiences of these patients and their perceptions regarding access to healthcare to determine the role that access to care played in their condition. Interviews were conducted to gain an understanding of their experiences related to their use of healthcare services. The narrative approach allowed recreation of 10 participants' personal stories. Findings show health literacy, lack of trust in the healthcare system, poor relationships with providers, unwillingness to adhere to medical advice, and inability to avoid conditions that cause ESRD were identified as barriers. Participants emphasized desires to help other African Americans avoid ESRD and its devastating life changing events. Additional qualitative studies are needed to capture more experiences of African Americans to help spread awareness to improve health literacy, incorporating enhanced cultural competence for healthcare professionals, and additional training in relationship-building to improve trust between patients and providers. Successful implementation of these social changes would potentially impact the African American community and healthcare professionals caring for them.

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Dedication

I dedicate the successful completion of this dissertation to all of the Walden Faculty that played a role in guiding me through all of the courses that lead up to this final outcome. I learned the value of perseverance and commitment and enjoyed their presence at the residencies. They freely shared their knowledge and expertise and clearly expressed the desire to see me succeed. My heartfelt thanks goes out to each one of them.

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I would like to thank my family, friends, and co-workers for believing in me and supporting me from start to finish. Although they were resting in heaven prior to the start of this degree, I thank my parents for teaching me to go for what I want and do my best while doing so. I thank my husband and kids for their patience and understanding when this journey required me to miss out on the things I enjoy most including family outings on occasion.

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Chapter 1: Introduction to the Study

Introduction to the Study

Healthcare has been a topic of discussion on several platforms for several years. More specifically, healthcare insurance coverage has been discussed and heavily debated in recent presidential elections, which suggests its importance. The 2010 implementation of the Patient Protection and Affordable Care Act (PPACA), more commonly referred to as the Affordable Care Act (ACA) or Obamacare, provided 50 million Americans with access to healthcare coverage that they may not have otherwise been able to access (Kominski, Nonzee, & Sorensen, 2016). Access to healthcare coverage or the lack thereof can make a difference in terms of health outcomes.

Kominski et al. (2016) indicated that prior to the implementation of the ACA, millions of Americans either had no healthcare coverage or not enough healthcare coverage. The ACA improved access to healthcare coverage for those not covered by private or public insurance (Kominski et al., 2016). Americans with health care insurance coverage who cannot pay for the costs associated with the coverage may think they do not have health care insurance. The ACA provides subsidies to many low-income insured individuals and expands eligibility for Medicaid coverage in some states (Kominski et al., 2016).

Health issues requiring medical attention should be properly addressed in medical facilities. The Office of Disease Prevention and Health Promotion (ODPHP) detailed access to healthcare services as one of the objectives of Healthy People 2020. Improvement of access to comprehensive and quality healthcare services can help prevents and manages disease, reduce unnecessary disability premature death, and achieve health equity for all Americans while promoting and maintaining health (ODPHP, 2018). Access to comprehensive and quality healthcare services includes insurance coverage, medical care, and timely delivery of care (ODPHP, 2018). Americans need insurance coverage to gain entry into the health care system in a timely manner, need availability of a provider geographically located, and need the ability to build a relationship with the provider based on trust and ability to communicate. According to the ODPHP (2018), access to health care impacts quality of life if these things are not present.

There are barriers and factors in terms of why Americans do not seek proper healthcare other than the high cost of care and no insurance coverage. Barriers such as lack of availability of services and lack of culturally competent care must also be noted. These barriers lead to health conditions that go untreated, untimely care, preventable hospitalizations, and financial burdens (ODPHP, 2018).

In addition to these barriers and factors is the fact that the U.S. population is living longer. With longevity comes additional health conditions that must be addressed by healthcare professionals. The elderly population of ages 65 and older often suffer from end stage renal disease (ESRD) In this study, the researcher sought to gather the experiences of African Americans diagnosed with ESRD and their perspectives involving access to care to gain an understanding of the impact access to care had on their conditions as well as determine strategies to establish an educational program to help improve health outcomes for this population.

Disparities in terms of age, sex, ethnicity, race, education, and family income exist with all levels of access to care including having an ongoing source of care and access to a primary care provider. Without having knowledge of how and where to access care as needed, allows these disparities to remain. Health disparities, as experienced by socially disadvantaged populations and defined by the Centers for Disease Control and Prevention (CDC, 2018), are preventable differences in terms of burden of disease, violence, injury, or opportunities to achieve optimal health. Health disparities are similar to disparities and barriers. Americans with health disparities also rely on access to health care services and insurance coverage to confidently and comfortably enter into the health care delivery system, build a trusting relationship with a primary care provider, and continue to seek medical care in a timely manner from that provider (CDC, 2018).

Background

According to the NKF (2016), African Americans lead all races in terms of prevalence of ESRD. Despite the fact that African Americans make up 13.2% of the U.S. population, they account for 35% of all ESRD patients (NKF, 2016). ESRD is the final phase of kidney disease. Treatment by renal replacement or kidney transplant is required to sustain life. Two conditions that often have no symptoms and are the leading causes of ESRD are diabetes and hypertension (NKF, 2016). Absence of symptoms allow these conditions to go unnoticed and therefore untreated. The absence of proper healthcare treatment of these conditions can lead to kidney failure, which can then escalate to ESRD (NKF, 2016). This suggests that proper healthcare is either not being sought or received by African Americans.

The intent of this study was to capture the perspectives of African Americans diagnosed with ESRD and their perceptions regarding the accessibility of healthcare and if there was an impact on their health. The researcher gained an understanding of the factors that impede or facilitate access to care, including any disparities as defined by participants. This chapter details the purpose of the study, research questions that were addressed, the framework, nature of the study, and operational definitions of terms used throughout the study.

Problem Statement

The prevalence of patients diagnosed with ESRD continues to increase. African Americans lead all other races with this condition and these cases continue to rise at an alarming rate according to the National Kidney Foundation (2016). Proper medical care allows for timely diagnosis and treatment of conditions that lead to this disease (NKF, 2016). The African American population is either unaware of the causes of this disease or not receiving proper medical care or both.

Purpose of the Study

The purpose of this qualitative narrative research study was to capture and explore the perspectives of African Americans diagnosed with ESRD to gain an understanding of the factors that facilitate or impede accessibility of care to determine if access to care played a role in their condition. The intent of the study was to determine, upon analysis of findings, strategies to execute to create an educational program to address the findings for improved health outcomes for the African American population.

The narrative design was used to recreate the experiences of the African American participants to help spread awareness of ESRD.

Research Questions

The two research questions that lead to the development of strategies in this narrative research study were:

RQ1: What role does accessibility of care play in terms of experiences of African Americans diagnosed with ESRD? Participant responses to interview questions related to access to health care may allow researcher to capture the perceptions of how strongly the participant feels about the access he/she has to medical care, how that access relates to their diagnosis, and what program can be created for education, awareness, and improvement. *RQ2:* What factors influence accessibility of care for African Americans diagnosed with ESRD? Participant responses to interview questions related to reasons why African Americans seek health care may allow researcher to identify the factors that had an impact on the participant's ability to seek health care and determine the need for further research or the type of program to create to address the factors to assist with improving access to health care.

Conceptual Framework

The conceptual framework used in this study was Andersen and Newman's framework of health services utilization. This framework involves predisposing, enabling, and need factors that either facilitate or impede use of health services as perceived by the individuals themselves (Andersen & Newman, 1995). Utilization to health services based on the factors identified by Andersen and Newman may be reflected as dependent or independent variables upon completion of the semi-structured interviews in the narrative research study conducted.

Andersen and Newman (1995) identified the most immediate cause of health service use is generated from functional and health problems. The perception of the need for health services is determined by the patient along with adherence to a medical regimen and care seeking after visiting a medical provider (Andersen & Newman, 1995). Attitudes towards the healthcare system, means and knowledge regarding how to access health services, and availability of health personnel and facilities and a reasonable wait time are factors Andersen and Newman suggest exist prior to the patient’s illness.

Nature of the Study

The nature of this study was qualitative using a narrative research design. Use of the narrative research design allowed the researcher to address the research questions and relay experiences captured and shared by participants during interviews once results and findings were analyzed. This qualitative research method best allowed the researcher to recreate the perceptions of participants in terms of how access to care played a role in their current health conditions. The narrative research design was specifically chosen over the phenomenological design to allow the researcher to recreate stories of participants using data and observations captured during face-to-face interviews. The phenomenological design would have allowed their experiences to be captured; however, the ability to share the findings as a narrative would also allow the researcher to incorporate personal experiences with the condition and relate them to family history.

A qualitative study design was chosen based on the absence of qualitative research involving experiences of African Americans with ESRD. Given the increasing prevalence of this condition within this population, several quantitative studies and results are reported, but none include a focus only on this population with this condition.

Definitions

The following terms that were used throughout this study are defined:

Access to care: The ability to acquire medical attention needed to improve or sustain medical conditions.

African American population: Participants who identify themselves as either black or African American.

End Stage Renal Disease (ESRD): According to the NKF (2016), ESRD is defined as the final phase of kidney disease at which point the kidneys no longer function to capacity and without medical treatment or a kidney transplant, the condition is terminal.

Health disparity: Preventable health differences in terms of burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations (CDC, 2018).

Patient Protection and Affordable Care Act (PPACA): Comprehensive healthcare reform law enacted on March 23, 2010. The ACA is the amended version of the law as of March

30, 2010. Obamacare is the term the ACA is often called by both supporters and nonsupporters of the law.

Assumptions

Assumptions for this qualitative research study include the potential for selected participants to not understand their condition, including its severity and not have healthcare coverage, or those with healthcare coverage may not understand their healthcare benefits. These assumptions were critical to the meaningfulness of the study because it was important that participants understand the information being sought during the study. Questions specifically involving these assumptions were necessary to gain an appropriate account and understanding of their experiences. An introductory discussion either during the recruitment process or preceding the start of the semi-structured face-to-face interviews allowed the researcher to identify and address these assumptions or incorporate that information in the results of the study.

Scope and Delimitations

ESRD affects all races. This study was delimited to African Americans diagnosed with ESRD because of the prevalence of this condition among this population and the increase of numbers diagnosed. The scope of this study was African Americans undergoing hemodialysis which is the most common form of treatment for ESRD. These African Americans were in scope because of the recruitment process. The recruitment process consisted of a flyer that was shared in a dialysis facility. It contained criterion for participation and contact information for the researcher. In addition to this scope and delimitation, researcher avoided bias by not focusing on family members with ESRD which was the recommendation of several Walden faculty members.

Limitations

A potential limitation for this qualitative study was that the small sample size was recruited from only one dialysis facility in Detroit, Michigan; therefore, this study selection may not be representative of all African Americans. It should still, however, set the foundation for future studies or policies to educate this population for better health outcomes. Future studies could include a larger sample size from multiple dialysis facilities and be done in the form of a focus group. In addition, according to Creswell (2014), when conducting interviews, not all participants are equally articulate and perceptive. The potential limitation that participants may not be able to articulate and explain their perceptions was difficult to measure until the actual study was underway, but the inclusion of such participants was imperative to determine the constant increase in patients among this population diagnosed with this condition.

Significance

Experiences of African Americans diagnosed with ESRD provide knowledge about their ability to access medical care in terms of their perceptions of access and appropriate care. Gaining an understanding of what they perceive as access and appropriate care helped explain the increasing prevalence of this condition in this population. The findings may also help health care professionals provide educational opportunities to other African Americans regarding care required to prevent conditions that lead to ESRD and treatment options if diagnosed. Researcher identified the need for further research to address the absence of literature on this population with this condition to confirm or disconfirm findings as a result of this qualitative study.

NKF (2016) reported that numerous quantitative studies have been conducted that report the number of African Americans and other races with health conditions that lead to ESRD and their accessibility to care but none have focused on African Americans with ESRD. The original contribution provided by this study is awareness based on the focus on this population and their perceptions of the accessibility of care. Upon completion of this study and after gaining an understanding of the factors that facilitate or impede accessibility of care for African Americans diagnosed with ESRD, the researcher may be able to help this population understand how to successfully manage the healthcare delivery system and gain access to appropriate healthcare to manage their health conditions. This study may lead to social change through the implementation of an educational program designed to share gathered experiences to assist health care professionals servicing African Americans better serve these patients. Implementation of such an educational program could assist African Americans with accessing appropriate medical care and improved health outcomes as determined by their experiences.

Conclusion

In summary, this chapter included background information on ESRD and the African American community that led to the reason for conducting this qualitative study. Researcher identified that African Americans have higher rates of ESRD than other races. Researcher sought to gain an understanding of reasons why African Americans lead other races with ESRD and the role access to health care played in their condition. Chapter 2 includes a detailed review of the peer reviewed literature regarding accessibility of care and the role it may play on health outcomes for ESRD patients as it relates to the African American population. Chapter 2 also includes methodological literature about African Americans' history of leading races with other health conditions, including the two main conditions that cause ESRD.

Chapter 2: Literature Review

Introduction to the Literature

This chapter provides an overview of literature regarding the topic. Research shows that similar studies have been conducted using quantitative methods to report the number of impacted African Americans facing barriers and factors in relation to access to health care and various health conditions. This chapter includes the literature review strategy, framework for the study, a review of research literature and methodological literature specific to the topic, and a summary of reviewed literature. The researcher's goal in this chapter was to capture and share literature as it relates to participants of the study being conducted with a focus on the gap in the literature.

Literature Review Strategy

A literature review was performed using peer-reviewed articles and journals from the Walden University Library, Central Michigan University Library, and South University Library. Searches included key terms related to healthcare use such as *access to healthcare services*, *medical care utilization*, *factors in healthcare*, *barriers to access to healthcare*, *health determinants*, *African American healthcare,* and *end-stage renal disease*. The search was limited to peer-reviewed publications within the last 5 years to capture the most recent literature to identify the gap and potential need for further research and aid in creating an educational tool to address issues identified in study to help improve health outcomes.

Framework

Andersen and Newman’s healthcare utilization framework includes the ability to seek care despite the level or degree of the medical need at the time. This framework has expanded into multiple phases over several years. The current phase describes the access to and use of health services of an individual using three characteristics: predisposing factors, enabling factors, and need factors.

Predisposing factors are sociocultural characteristics that exist prior to an individual’s illness (Andersen, 1995). Examples of predisposing factors include education level, occupation, attitudes towards the healthcare system, and demographics such as age and gender (Andersen, 1995). The logistical aspects of obtaining care were categorized as enabling factors which include knowledge of how to access health services, insurance coverage, available health providers, waiting times, and possible additions such as genetic factors and psychological characteristics (Andersen, 1995). The third and final factor that Andersen described as the need factor is one where an immediate need dictates when medical care is perceived as needed. Perceptions of one’s own health, functional state, symptoms, and pain experienced dictates whether the individual seeks professional help. Andersen and Newman’s framework detailed factors leading to reasons that facilitate or impede the decisions patients utilize health care services. This was the foundation of this study which allowed the researcher to determine if patients’ use of healthcare services played a role in their diagnosis of ESRD.

Review of the Literature

Contrary to the factors identified by Andersen and Newman's healthcare utilization framework, Hansen, Hodgson, and Gitlin (2015) examined the perceptions of older African Americans and their level of trust with healthcare providers. They conducted and transcribed semi-structured interviews and found that provider behaviors lead to mistrust by African Americans for reasons such as erroneously assuming stereotypical preferences and competence, inadequate time spent listening to patients, disregarding patient preferences, and insufficiently explaining treatments. The ODPHP (2018) reported, in the Healthy People 2020 overview, health disparities in the African American communities that closely align with the behaviors described by Hansen et al., (2015) that lead to mistrust of the health care providers. Hansen et al., (2015) reported that improved trust, satisfaction with care, and health outcomes were critical and direct results of effective communication between older African Americans and healthcare providers.

Methodological Literature

The methodological literature specific to the topic on which the research questions were based, contained reported that health disparities leading to factors that control or limit participants' views or not played a vital role in the health outcomes and questions for the study. Health disparities, as identified by the CDC (2018), result from multiple factors including inadequate access to healthcare. Inadequate access to healthcare and untimely health care lead to similar results. Shannon (2018) identified that effective healthcare requires that those in need have timely access to it. The inability to access health care can lead to short-term effects on health (Shannon, 2018), but with conditions such as ESRD, the long-term effects on health are terminal.

Nee, Yuan, Hurst, Jindal, Agodoa, and Abbott (2017) assessed the impact of poverty on the racial/ethnic disparities in pre-ESRD nephrology care given to minority populations who are disproportionally affected by chronic kidney disease. Nee et al. (2017) also reported adverse clinical outcomes in patients with ESRD given the interdependency of race, ethnicity and socioeconomic factors. Brown and Cappelletti (2013) identified that asthma, another chronic condition prevalent among the African American population, requires adequate access to healthcare for better health outcomes, yet this population is underrepresented in clinical asthma studies, lacks sufficient asthma management guidance from their physicians, and have poor adherence to asthma medications.

ESRD has been labeled as one of the starkest examples of racial/ethnic disparities in health according to Norris, Williams, Rhee, Nicholas, Kovesdy, Kalantar-Zadeh, and Boulware (2017). Norris et al. (2017) identified that substantial racial differences persist in dialysis quality measures despite improvements over the last 25 years. African Americans suffer from ESRD at higher rates than other nonminority populations in the United States as a result of these health disparities (Norris et al., 2017). Large racial disparities in dialysis adequacy were noted when comparing Whites and African Americans over 20 years ago (Norris et al., 2017). African Americans most often seek in-center hemodialysis as treatment for their ESRD which is less desirable but most common. They are less likely to seek kidney transplantation or home dialysis therapy like their White counterparts which highlights the need for continued efforts to achieve greater equity in the use of the preferred options for ESRD care (Norris et al., 2017).

Suurmond, Rosenmoller, el Mesbahi, Lamkaddem, and Essink-Bot (2016) conducted a cross-sectional analysis to describe language barriers in health care. Suurmond et al. (2016) argued language barriers in healthcare are a global problem that is growing and impacts access to healthcare. Similar to language barriers, Caldwell, Ford, Wallace, Wang, and Takahashi (2016) conducted a study to determine the association between social conditions and disparities in access to health care for African Americans living in rural areas compared to those living in urban areas which conferred additional disadvantage for those in rural areas. Brown - Walker (2015) conducted a qualitative, hermeneutic phenomenological research study which identified themes surrounding barriers to health care access including fear, mistrust, and disrespect issues which are similar to previously reported findings. In addition, Brown-Walker indicated that her research showed that said distrust of the healthcare system plays a significant role in healthcare access.

Travers, Cohen, Dick, and Stone (2017) researched the width of the disparity gap between African Americans and Whites to determine if it still exists. Travers et al. (2017) used eight years of National Health Interview Survey data gathered from an annual cross-sectional survey of U.S. households. This date span in particular was during the Great Recession in America (Travers et al., 2017). Their intent was to examine healthcare utilization and changes in racial disparities among these populations before, during, and after this time (Travers et al., 2017). Financial stability in the U.S. was disrupted during this economic recession which also made it challenging for many Americans to maintain adequate health insurance coverage (Travers et al., 2017). Loss of health insurance coverage and other hardships caused a decline in healthcare services, despite an identified need for the care, because of costs (Travers et al., 2017). Travers et al. (2017) posited that the impact from the Great Recession took a greater toll on African Americans than on Whites. Existing health disparities may have resulted from the reduction in care seeking behaviors by racial minorities during the Great Recession (Travers et al., 2017).

African Americans' choice to forgo medical care that they need normally includes the ability to afford the care while poor quality healthcare services may also affect it (Travers et al., 2017). Travers et al. (2017) noted that African Americans, when compared to Whites, experience dissatisfaction with care causing them to prioritize other costs ahead of what they perceive as less than optimal healthcare quality. Literature shows a common finding of decreased access to care for African Americans compared to Whites and increased financial constraints in obtaining needed medical care (Travers et al., 2017). Subsequent efforts to decrease healthcare disparities require an understanding of healthcare utilization patterns such as these studied before, during, and after the Great Recession (Travers et al., 2017).

In addition to health disparities, forgone medical care, and healthcare utilization patterns as shared by Travers et al. (2017), mistrust of the healthcare system plays a vital role in the African American patients' healthcare experience (Murray, 2015). Murray identified that unmet needs or poor treatment in a healthcare experience affects the ability and willingness of the individual to trust. She explored the concept of trust using Walker and Avant's (2011) concept analysis methods. This concept is applied to healthcare experiences of African Americans with discussion of opportunities for building trust.

Murray (2015) defined trust as "the willingness to enter a dependent relationship to have needs addressed and maintained by met expectations" (p. 285). She detailed methods for building trust and consequences of mistrust. African Americans have a history of mistrust following experiences with slavery and medical experiments like the Tuskegee Syphilis study according to Murray (2015). Both of these instances were rooted in deplorable health conditions and dishonesty. Murray (2015) categorized African Americans' mistrust of the healthcare system as *chronic* following a cross-sectional study. She added that this chronic mistrust may contribute to the health disparities of this population.

In addition to health disparities and medical mistrust identified by Murray (2015), Arnett, Thorpe, Gaskin, Bowie, and LaVeist (2016) explored the differences between Whites and African Americans and their main source of care. Arnett et al. (2016) established that racial disparities exists in medical mistrust. They established that African Americans have a greater mistrust than Whites and serves as an explanation for their reluctance to participate in medical research. This medical mistrust correlates to African Americans having higher utilization of the emergency department, lower rates of preventive services, and fewer health-seeking behaviors in comparison to their White counterparts who maintain a relationship with their primary care physician (Arnett et al., 2016). There have been several studies that established that high levels of medical mistrust predict lower utilization of preventive care services and less preventive care leads to high occurrence of medical issues that might have been prevented." (Arnett et al., 2016).

Adherence to treatment is also important for positive health outcomes. Daniels, Robinson, and Walker (2018) reported that ESRD is a challenging disease which is difficult to manage and requires lifestyle changes to live. Complexities with this disease have been acknowledged by patients and healthcare providers (Daniels et al., 2018). Modifications and restrictions to dietary, including fluid intake, adherence to medication and strenuous treatment schedules are examples of life-altering changes required of ESRD patients (Daniels et al., 2018).

Daniels et al. (2018) conducted a study to assess adherence in African Americans with ESRD since they have a higher incidence of the disease, are at a greater risk of suffering from complications and health disparities, and few studies focus on this population. Findings from their exploratory, descriptive study revealed that patients find it difficult to adhere to all aspects of treatment, noting that adherence varied among all restrictions. An individual's perception of illness is also an aspect of adherence (Daniels et al., 2018). Daniels et al. (2018) reported that African Americans with higher perceptions of illness chronicity also had higher perceptions of adverse consequences of their illness. Communication with healthcare provider was reported as frequent but participants reported that a more formal process to ensure understanding and reinforce adherence should be implemented (Daniels et al., 2018).

Conclusion

In summary, a review of the peer reviewed literature suggest that there are several reasons why patients seek health care in the manner in which they do or decide not to. Research shows that several different chronic health conditions that require access to care to prevent the condition from arising or prevent the condition from worsening, require timely, access to health care services and clearly explained treatment options. Health disparities and other barriers have been identified by several researchers and in many cases their findings mirror each other with an exception of location, health condition, and specific population studied.

Chapter 3 explains the methodology used in the qualitative research study conducted to capture the perspectives of the African Americans and their perceptions on their access to health care. The study focused specifically on African Americans diagnosed with ESRD because research shows that many quantitative studies have been conducted to report the number of impacted African Americans but qualitative research is required to capture their perspectives and explore their perceptions of their condition and the healthcare they have received.

Chapter 3: Research Method

Introduction to the Methodology

It has been discussed in Chapters 1 and 2 that there is a need to know why African Americans lead all other races diagnosed with ESRD. Chapter 2 identified the factors that can either facilitate or impede access to healthcare and the role those factors can play on appropriate use of medical care. Chapter 3 contains a detailed account of the research design and rationale, role of the researcher, research method used in the study, target population and participant selection, procedures and instruments used, and research questions that the study addressed.

The purpose of this qualitative study was to gain an understanding of the factors that facilitate or impede accessibility of care for African American patients who have been diagnosed with ESRD to determine what if any role access to healthcare played in their condition. The prevalence of ESRD among the African American population exceeds all other races. This suggests the need for further research with this population to determine the cause.

Research Design and Rationale

The researcher used the narrative design to address two research questions that may lead to the development of strategies to deliver better health outcomes for the African American population diagnosed with ESRD.

RQ1: What role does accessibility of care play in terms of African Americans diagnosed with ESRD?

RQ2: What factors influence accessibility of care for African Americans diagnosed with ESRD?

Using the narrative research design, the researcher studied the lives of participants, gathered their perspectives about their condition and access to healthcare, and then recreated their stories in a narrative chronology. Narrative research, according to Ravitch and Carl (2016), "methodologically gives primacy to the lived experiences of individuals as expressed in their stories" (p. 23). The phenomenological approach was considered since it focuses on human experiences as described by participants, but the rationale for using the narrative design was to recreate participants' experiences and tell their stories as depicted through face-to-face interviews.

Neither ethnography nor grounded theory were considered for this study because they did not match the researcher's focus for the study. Ethnography's emphasis on in-person field study, participant observation, and cultural portrayal would not allow researcher to capture, understand, and recreate experiences and perspectives of participants based on their conditions. The emphasis was placed on input provided by participants. Grounded theory focuses on the development of theories and involves specific procedures (Ravitch & Carl, 2016). Theories may be identified and even included in the final report of results, they were not the focus of the study. Face-to-face interviews were conducted instead of focus groups or case studies because they allowed for privacy of participants to be comfortable, open, and honest while sharing their personal experiences regarding their conditions and access to healthcare.

Role of Researcher

The role of the researcher in this qualitative research study was to capture and assess thoughts and feelings of participants regarding the phenomena of interest. As the primary data collection instrument, the researcher recreated personal stories of participants. Data gathered from participants required safekeeping and that their privacy be protected. This is the primary responsibility of the researcher. The researcher communicated to participants prior to starting each interview that results would be shared in addition to any program created to address the findings.

Methodology

The methodology for this study was qualitative. Qualitative researchers "aim to understand individuals, groups, and phenomena in their natural settings in ways that are contextualized and reflect the meaning that people make out of their own experiences" (Ravitch & Carl, 2016, p. 2). They inquire and seek to discover and describe through narrative reporting what people do in their daily lives and what their actions mean to them (Ravitch & Carl, 2016). Qualitative researchers explore their interests in people's subjective interpretations of their experiences, events, and actions rather than the quantity of people impacted by the events as studied in quantitative research.

The population studied was African Americans in Detroit, Michigan diagnosed with ESRD. A purposeful sample of 10 participants age 18 years or older was recruited from a dialysis facility in Detroit. The recruitment process involved flyers containing background information about the researcher and study as well as information explaining opportunities to participate in the study and processes to follow for participation. In-person communications with staff of the dialysis facility took place prior to all recruitment attempts to establish protocol.

The study included in-depth semi-structured interviews conducted face to face using open-ended questions to elicit perspectives and perceptions from participants. Observations of participants' body language and immediate use of follow-up and probing questions were recorded. The researcher created an interview protocol, questions, and follow-up procedures as well as observation sheets for notetaking. The setting of the semi-structured interviews was an agreed upon location that was safe and free from noise and distractions. This provided both privacy and a quiet setting for legible audiotaping and transcribing. The researcher analyzed and transcribed the audiotaped interviews by hand, compiled the findings in categories and themes, and created an educational program based on the results.

Issues of Trustworthiness

Trustworthiness is important in qualitative studies because participants share their personal experiences with the researcher. Trustworthiness was built and measured in this study by a) thoroughly explaining reasons for the study to participants during the recruitment process, b) providing details of the interview process, including the need for audio-taping and notetaking during the interview, c) emphasizing privacy protection, and d) providing data following analysis to address findings upon conclusion of the study.

Participant Selection

African Americans aged 18 and older currently being treated for ESRD were chosen for participant selection. This delimitation avoids the need for parental permission while allowing the opportunity for a larger group of participant perspectives to be captured. Participants were purposefully selected from a dialysis facility in Detroit, Michigan based on willingness to participate. They were recruited through flyers which were posted in the facility with the permission of faculty. These flyers explained the study and requested that those interested in participating contact the researcher with their availability and contact information. Potential participants were required to be able to read and understand English as determined by their responses to the recruitment flyer, which was typewritten in English.

Target Population

The target population for this study was the African American community. This population will be provided access to the findings of the study. This African American population may use these findings to prevent the prevalence of conditions such as ESRD and the conditions that lead up to this disease.

Conclusion

In summary, during this qualitative study, the researcher transcribed interviews and then identified, examined, and analyzed any themes and categories to determine the factors that facilitated or impeded access to healthcare according to participants. The researcher will make the results available to the participants, this population, and healthcare professionals with the intent to create a program to educate both healthcare professionals and the African American population regarding the importance and means of accessing healthcare services as needed to improve health outcomes. By the end of this study, it was evident that further research is required to provide a) evidence of identified factors, risks, and health disparities addressed for this population, and b) action taken to correct/adjust the mistrust of the health provider to build and repair relations with their patients with effective communication and time commitment.

Chapter 4 includes results from the interviews conducted, transcriptions and themes identified while transcribing the interviews. The results shared in Chapter 4 reflect direct quotes from participant responses in relation to the research questions that helped to create the strategy of this study. In addition, Chapter 4 closes with the researcher discussing evidence of quality including trustworthiness, privacy of participants' information, and the availability of the findings following completion of the study.

Chapter 4: Results

Introduction to the Results

In Chapter 3, it was explained that semi structured interviews were conducted to gather experiences of African Americans diagnosed with ESRD and their perceptions of access to healthcare. The purpose of this study was to gain an understanding of whether access to healthcare played a role in their conditions by impeding or facilitating the care they received. More specifically, the researcher aimed to determine if African Americans lacking access to healthcare are more apt to suffer from the conditions that lead to ESRD or are more likely to be diagnosed with ESRD despite having access to healthcare and healthcare education, transportation, awareness of treatment plans, and healthcare insurance.

This chapter contains information about participants, details from the interview process, transcription procedures, results of interviews in the form of themes and patterns identified in individual participant transcriptions, and evidence of quality. The results were gathered and analyzed to answer these two research questions:

RQ1: What role does accessibility of care play in terms of experiences of African Americans diagnosed with ESRD?

RQ2: What factors influence accessibility of care for African Americans diagnosed with ESRD?

Interviews

Following IRB approval, African Americans diagnosed with ESRD age 18 and older were recruited for participation using flyers detailing the study. Recruitment took longer than anticipated and was challenging due to established research and privacy processes for each dialysis facility approached for participants. In addition, some participants who agreed to take part and scheduled their interviews became ill and required hospitalization.

The semi structured interviews were conducted between December 2019 and March 2020. Before the start of each interview, participants consented to taking part in the interview and agreed to allow audio recording and notetaking to not miss any details shared or expressed. Interviews opened with an explanation of why the study was being conducted, the researcher’s academic goals, and a brief explanation of results upon completion of the dissertation as a whole. Starting in this manner provided the researcher the opportunity to build comradery with participants by answering any degree-related questions while also setting a relaxed atmosphere. Participants verbally expressed a genuine desire to help me meet my educational requirements for degree completion.

Open-ended questions were used to gather detail regarding participants’ experiences with this condition and access to healthcare. Interviews lasted between 10 and 33 minutes. Interviews started with an introductory question. The researcher asked participant to tell a little about themselves. Use of this introduction question garnered responses to actual interview questions that no longer needed to be asked. Participants spoke freely regarding their medical and family history, current health conditions, and future plans to maintain life as close to normal as possible. All audio-recorded interviews were saved on a password-protected tablet and laptop for safe and proper storage for 5 years as required by Walden University.

Transcription

Upon completion of each interview, audio recordings were transcribed by hand as well as using any handwritten notes. Transcribing by hand involved several replays of the recording in order to capture verbatim what the participant said, including any vocalized reactions such as sighs or chuckles. While this process was time-consuming, it was the best way to recreate both the experience of the interview itself as well as experiences shared by interviewees. Having another person or a computer program transcribe the audio recording would have taken away from the relationship built between the researcher and interviewees and unmasked their anonymity as promised at the top of the interview. All transcriptions were typed in Microsoft Word and saved on a password-protected tablet and laptop for safe and proper storage for the 5 years required by Walden University.

Table 1 contains details regarding the 10 participants of this study. Marital status was not a criterion for participation, but the interview began by asking that the participant tell a little about himself/herself. Nine of the 10 participants included their marital status in their response. I included this characteristic because it was later deemed pertinent in terms of their descriptions of their support system or lack thereof.

Table 1

Participant Characteristics

Participant	Age	Gender	Marital Status
1	71	Female	Unknown
2	66	Female	Divorced
3	33	Female	Single
4	59	Male	Married
5	55	Male	Single
6	21	Female	Single
7	46	Female	Single
8	73	Male	Married
9	49	Male	Single
10	78	Female	Married

Themes and Patterns

Once interviews were transcribed, a thorough analysis of the transcriptions was conducted and coded. Coding included highlighting similar words or statements and assigning themes based on identified patterns. Identified themes were a) attitude towards life after being diagnosed, b) desire to get a transplant, c) inconvenience due to multiple doctor visits, d) support group for encouragement, e) lifestyle change is mandatory, f) lessons learned and shared, and g) advice to others for avoidance. Definition of these themes and responses shared by participants are detailed here.

Attitude Towards Life After Being Diagnosed

Attitude towards life after being diagnosed was chosen as a theme following the coding of many participants describing the atmosphere of their treating dialysis facilities and thoughts of other patients using adjectives such as dark, without despair, hopeless, and sad. It was mentioned by Participant 6 that the way ESRD patients approach dialysis and the condition as a whole has a direct result on their attitude. Participant 2 compassionately expressed, “My dialysis family helped to change my attitude because I was on the verge of giving up." Participant 1 described her attitude about dialysis as, "When I first walked into the dialysis facility, I thought the world was ending as I looked around at the other patients because they looked so down." Participant 5 emphasized, "So many people don't take dialysis serious enough or at all. They have not changed their attitude about living and in order to live, I know I must do dialysis." Participant 8 explained, "I try to stay positive and lean on my faith. That's the attitude I like to keep."

Desire to Get a Transplant

Desire to get a transplant was chosen to capture the emphasis many participants placed on the discussion around a kidney transplant. Nine of the 10 participants mentioned the desire to get a transplant instead of continuing to have dialysis treatments. This discussion prompted participants to explain their experiences with required testing to get on a transplant list, willingness of family members to get or consider testing as a possible donor, and the unwillingness of family members to consider testing as a donor. Participant 1 shared with emphasis and anger, "I have seven siblings with health issues unrelated to being a donor and they won't even (expletive) consider getting tested to be a (expletive) donor!" Participant 3 declared, "There are so many tests to take to get on the list and I have gone through them all and my doctor keeps coming up with more. I plan to do as many tests as he says I need." Participant 4 shared, "My uncle had a transplant and died six months later so although I don't want to keep doing dialysis, I am having second thoughts about having a transplant." Participant 10 explained, "I would love to have a kidney transplant but I am overweight and have other conditions but I am trying to work on all of these things to make it happen."

Inconvenience Due to Multiple Doctor Visits

Dialysis treatments were described by participants as inconvenient because it occurs three days a week for four or more hours each day. In addition to the dialysis treatments, participants mentioned several other health conditions that require multiple doctor visits. Most identified the number of hours spent seeking medical care and the effort it takes to travel to those appointments using transportation services as “discouraging” and “inconvenient”. Preparation for dialysis treatments and doctor visits were also described as inconvenient by four of the participants. Participant 6 exclaimed, “I have so many appointments that it feels like all I do is go to the doctor and dialysis and nowhere else.” Participant 8 angrily stated, “My doctor makes me come in every month just to get scripts and make me wait a long time in the lobby for a five minute script to be written knowing my transportation and fixed income situation and the script is only for 30 days!” Participant 10 mentioned, “I have to depend on transportation services to get to and from my dialysis treatments and sometimes they just don’t come for hours to pick me up.”

Support Group For Encouragement

Undergoing hemodialysis requires a support group to encourage patients to maintain the appropriate diet (including fluid intake), medication regimen, and keep all scheduled doctor appointments according to several of the participants. Nine of the ten participants introduced themselves as married, divorced, or single. During the interviews, it became clear why this information was important enough to be shared. The three married participants expressed the role that their spouses played in their care and gave reasons why they feel they couldn't make it without them and feel encouraged to do the right thing for them (their spouse). The single participants described a grimmer outlook on life as if to suggest they have no one to push them or no reason to follow directives given by their doctors.

Family was described as very important by 8 of the 10 participants which made them feel "committed to being at every dialysis treatment." Two participants described their dialysis center as family because "they spend so much time there and had been going to the same facility for so long." Participant 2 shared, "I love my family and all but they just don't get it. They don't understand what it's all about so I just try to encourage them to stay healthy to avoid this." Participant 7 boasted, "My dialysis friends is like my family because I see them more than I see my regular family." Participant 9 exclaimed, "I have made some very close friends at my dialysis center that I consider family. They encourage me to keep coming because it is life-saving!"

Lifestyle Change is Mandatory

Participants were emphatic about the lifestyle changes required to live their life as close to normal as possible with this condition. Lifestyle changes such as watching what they eat, watching what and how much they drink, and being mindful of taking care of the other health issues that lead to this condition were among the list of "must dos" according to the participants. Participant 1 exclaimed, "I used to travel a lot but now I can't travel because I can't miss those treatments and I can't afford to schedule the treatments where I am going because it costs more than he trip itself!" Participant 5 stated, "If I didn't have to do dialysis I could do more of the things I like to do but some days after dialysis, all I can do is rest." Participant 6 emphasized, "You must follow strict orders, no red meat, no pop or sugar and limit 32 ounces!"

Lessons Learned and Shared

Lessons learned was the theme used to define statements and phrases where the participants recapped actions taken or avoided prior to their ESRD diagnosis. Eight of the ten participants described the fact that they failed to go to the doctor as needed prior to being diagnosed with ESRD despite being aware of underlying conditions that lead to this disease. One participant admitted that "he avoids going to the doctor at all costs" and another described herself as "very healthy prior to being diagnosed with ESRD." Participant 1 exclaimed, "I was rebellious about getting on dialysis. My doctor told me for 8 or 9 months that I needed to start and I delayed, delayed, delayed!" Participant 3 indicated, "I had to tell the nurse practitioner in the office that I didn't need a go between. I need to see the actual doctor instead because I had been seeing her for far too long!" Participant 7 expressed, "When the doctor told me that my numbers were bad, you know, my diabetes numbers, I should have done more then!"

Advice to Others For Avoidance

Advice to others was a theme birthed from several participants simply stating what they would advise other non ESRD patients based on their acceptance of their role and responsibility leading to this diagnosis. Participant 3 indicated, "If I could give advice to someone whose doctor has told them that their results indicate their kidneys are bad, I would tell them to do whatever they could to turn things around." Participant 4 shared, "I advise everyone to take care of their kidneys because this is not a cakewalk."

Participant 5 mentioned, “If I could advise people not on dialysis to take care of themselves, I would tell them to go to their doctor, do what their doctor tell them to do to take care of their kidneys.” Participant 6 stated, “I tell my family to take care of themselves because this is a lifestyle change and not everyone can handle this.” Participant 7 advised, “Diabetes and blood pressure cause kidney damage so take care of your health, especially these conditions is what I tell people.”

Evidence of Quality

Trustworthiness as defined in Chapter 3 is important in qualitative studies. The procedures planned for the study were followed and participant experiences shared were kept safe and private. Trustworthiness was verified and measured by the participants’ willingness and agreement to take part in the study based on the thorough explanation provided during the recruitment process, detailed interview process including audio recording and notetaking, execution of the privacy protection, and the availability of the findings upon completion of the study and dissertation. Member checks in the form of follow up interviews were not required because clarification of responses were performed as needed during the interview and can be heard on the audio recording.

Conclusion

The results of this study allowed researcher to gain an understanding of the role access to health care played in the diagnosis of ESRD. Based on several responses from the participants of this study, it can be stated that these participants had access to health care and even went to scheduled appointments, and were aware of their medical conditions that lead to this diagnosis. What appeared to be the consensus of this limited population were the factors that may have impeded or facilitated their willingness to seek health care. Factors such as disapproval of the condition of the doctor's office, transportation issues and costs, and time spent waiting to be seen by the doctor impede their decision to go and continue to go. All participants declared that they go to all appointments despite these issues. Factors that facilitate their ability to access health care and the willingness to do so included a strong support group, more specifically a demanding and dedicated spouse, seeing to it that the doctor monitoring their care remain in control of their care and most common, the fact that their health care coverage covers all costs. According to the participants, having health care coverage did not help their current condition.

Chapter 5 contains an interpretation of the findings following an analysis of results and responses to the two research questions that lead to the study being conducted. Researcher provides a thorough introduction to the findings to explain the background of ESRD and the fact that African Americans lead all races with this condition. Chapter 5 concludes with recommendations and implications for positive social change which can be utilized by this population to help lessen the impact of this disease.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction to the Findings

Chapter 5 includes an overview of the findings of the study. ESRD is the final phase of kidney disease. It is the phase where the kidneys fail to function properly and without either renal replacement therapy (dialysis) or a kidney transplant, life cannot be sustained. The purpose of this qualitative narrative research study was to gain an understanding of why African Americans lead all other ethnic groups diagnosed with ESRD. Despite making up only 13% of the U.S. population, African Americans lead all ESRD diagnosed cases at 35% (NKF, 2016). African Americans also lead all other ethnic groups with diabetes and high blood pressure, which are the two conditions that lead to ESRD (NKF, 2016).

Due to limited qualitative research and literature on the African American population with ESRD, the researcher wanted to determine if access to healthcare played a role in their overall health or their current condition and gain an understanding of any factors that they perceived as barriers to access to health care. This would be accomplished by answering the two research questions that lead to the development of the study.

RQ1: What role does accessibility of care play in the experiences of African Americans diagnosed with ESRD? Participant interviews involved responses explaining where, when, and why they seek medical care. Most participants freely explained the care they currently undertake from doctors.

RQ2: What factors influence the accessibility of care for African Americans diagnosed with end stage renal disease? Participants were asked to share reasons that make them avoid seeking medical care." Researcher sought to determine if a set of circumstances caused these participants to not seek the care they needed which may have allowed their health condition to worsen and result in their ESRD diagnosis. Circumstances that are real (lack of finances) or perceived (no need for medical care), were examined during the interviews and will be discussed in this chapter.

This chapter includes an interpretation of the findings including themes identified, limitations of the study, recommendations for future research, implications for positive social change, and information to help address the problem facing this population. Chapter 5 also includes participant responses obtained directly from the interview transcripts. In addition to direct quotes, researcher also included non-verbal observations.

Interpretation of the Findings

In this section, the researcher provides a summary of interpretations of the findings following interviews of African American participants aged 18 and older diagnosed with ESRD and currently undergoing dialysis treatment. The intent of the study was to gain an understanding of the problem with the African American population leading all other races in terms of ESRD rates and the fact that the number of cases continues to rise. Ten participants were interviewed regarding their experiences as ESRD patients and perceptions involving access to healthcare. Interviews began with participants describing themselves. This opening question allowed participants to relax and freely express themselves by sharing as much or little personal information as they chose. All but two participants shared detailed accounts of their life including family, work, and health history, how long they had been ESRD patients, experiences with dialysis, opinions about kidney transplants, their faith, and support systems. More importantly, opening the interview with this question created a relaxed atmosphere and it allowed me to skip some interview questions because they were answered during the introduction. The two remaining participants shared some information but not in great detail like the others. The introduction also laid the foundation for a more guided set of follow-up interview questions as it became clear what was most important and meaningful to them as related to their condition and the research questions.

Marital status was not a criterion for participation but eight of 10 participants shared their marital status. Emphasis was placed on the importance of having a reason to adhere to medical requirements that accompany the condition. Family history, roles, and responsibilities were detailed in several ways during the introductions as well, which helped researcher to understand the importance of having a strong support system. According to participants, supportive spouses and family members assist them by giving them the drive and motivation they need to make required dietary changes for successful maintenance of improved health outcomes. They also provide help they need for transportation and other financial support. Two participants said that they had no family other than the family they have created at the dialysis center that they frequent three times each week. Participant 8 described himself as “a loner who only go out for dialysis treatments and doctor appointments." Participant 5 said, "I have been going to the same dialysis facility for almost 9 years so they are my family because I see them more than my actual family." She also said, "they give me hope because many of them been doing this longer than me and I used to want to give up because my body rejected it at first." All 10 participants mentioned that making a lifestyle change was a must after being diagnosed with ESRD. Most expressed the fact that had they made the necessary lifestyle changes to avoid getting diabetes and high blood pressure, they would not be in these major life changing situations today. Participant 10 described having dialysis treatments as "a life changing event that I would not wish on my worst enemy." She said, "This is not a cakewalk. They don't prepare you for this." Many participants placed great emphasis on the dietary changes required to avoid retaining too much fluid because it requires being on the dialysis machine for a longer period of time.

Following a thorough analysis of the results of interviews, themes were assigned based on patterns of repeated responses and similarities noticed in the transcriptions. The seven themes were attitude towards life after being diagnosed, desire to get a transplant, inconvenience due to multiple doctor visits, support group for encouragement, lifestyle change is mandatory, lessons learned and shared, and advice to others for avoidance. These themes were chosen while focusing on personal experiences described by participants within the context of interviews and in reference to the research questions. They helped the researcher separate and organize data throughout each transcription.

By definition, as shared in Chapter 4, these themes highlight repetition of experiences shared, descriptions of participants' understanding of their condition, and perceptions involving healthcare access and the healthcare system. Participants placed most emphasis on the fact that this condition and dialysis treatment is a lifestyle change that they would have never imagined. This section provides more details around the selected themes based on an analysis of participant experiences.

Theme 1: Attitude Towards Life After Being Diagnosed

During the interview process, researcher noted the participants' attitude based on their actions during interviews, descriptions of other dialysis patients they encounter on their weekly trips for treatment, mental goals they have set for themselves to approach each treatment, and their faith. Each participant described how their ESRD diagnosis changed their attitude towards life. Participants described, with either enthusiasm or despair, their approach to life when they go for treatments and other medical visits on a weekly basis. It is clear to these 10 participants that in order to live, they must attend all dialysis treatments until they get a successful kidney transplant. Given that fact and the fact that each described a kidney transplant as a desire but one that may never happen because of requirements and conditions that must change to be considered for a transplant, participants further described their attitudes as hopeful until a transplant occurs.

Theme 2: Desire to Get a Transplant

Participants all expressed the desire to get a kidney transplant to return their lives back to some form of normalcy prior to becoming dialysis patients. Their body language identified the discomfort in explaining how they feel their diagnosis of ESRD is their fault. Many participants displayed a nervous laugh or chuckle while they discussed the fact that they did not change their ways that lead to this diagnosis but are clearly aware of the fact that had they, their current health condition would be totally different today.

Theme 3: Inconvenience Due to Multiple Doctor Visits

Dialysis treatments, medical visits, and focus on dietary changes were all listed as inconvenient by all of the participants. The inconvenience results from the required dialysis treatments every other day for four hours and medical visits on the days they do not have dialysis. Attention to dietary intake plays a major role in the success of dialysis treatments but participants describe it as inconvenient because monitoring it is constant and crucial to sustain life.

Theme 4: Support Group For Encouragement

A good support group can be described as immediate family or close friends from the dialysis facility according to the participants but both are equally as important in the success of this treatment process. Participants with a support group reported more positive expectations than those with little or no support. Participants with a support group described feelings of encouragement and willingness to follow a strict healthcare regimen whereas those with no support described the ability to adhere to their doctor's orders as challenging.

Theme 5: Lifestyle Change is Mandatory

Lifestyle change appears to be the most recurring and important theme as it suggests that lifestyle changes made before being diagnosed as ESRD would have allowed the participants to avoid the lifestyle change resulting from the ESRD diagnosis. Making lifestyle changes such as dietary intake, exercise, and preventive services would have better health outcomes and potentially eliminate the diagnosis of diabetes and high blood pressure which cause ESRD. ESRD brings about required lifestyle changes that are nearly impossible to maintain in addition to the fact that the changes and dialysis treatments are what sustains life. Participants spoke passionately and in great detail about the lifestyle change resulting from ESRD. All participants expressed that they should have made lifestyle changes that would have allowed them to avoid this condition instead of the demands they now face and must accommodate to sustain their new way of life.

Theme 6: Lessons Learned and Shared

Lessons learned by these participants in relation to their current condition, the health care they received prior to this diagnosis, the required care they receive now, and the reality of it all, were expressed in their own way or in some cases the same manner. Many participants mentioned that had they known more about diabetes and high blood pressure and the impact these conditions have on the kidney, they would have made the necessary changes to avoid kidney disease. Each claimed that more knowledge about the conditions that lead to kidney disease would have made a difference in their current health and strongly feel that more education about these conditions would help others avoid kidney disease.

Theme 7: Advice to Others to Avoid This Condition

A strong message and advice to others to take care of their kidneys to avoid the constant increase in ESRD diagnosis cases was shared by each participant. Each declared the need for more education on the need for preventive services. It was strongly advised that primary care physicians emphasize the need to prevent diabetes and high blood pressure because medications to treat these conditions damage the kidneys.

An interpretation of the findings suggest that all of the participants are aware of the main diseases that caused their ESRD status: diabetes and high blood pressure. Each participant mentioned that both of these diseases affect other family members and had either caused other family members to also have kidney damage or are currently being treated for them. Nine of the 10 participants explained that they did not take their diagnosis of diabetes and high blood pressure serious enough to make the necessary changes to try to correct them. Participant 1 explained, “My doctor could not get my blood pressure under control at all. At one point I had to wear a helmet because I would pass out because it was so high and I had to protect my head. I knew I would have kidney damage because I did my research and knew that the medicine was damaging my kidney.” Participant 2 explained, “I was healthy until being diagnosed with ESRD but then I realized I wasn’t healthy but I hadn’t been to the doctor to know that I wasn’t. Had I just gone to the doctor for preventive visits this would not have happened to me.” Participant 4 stated. “I avoid doctor offices at all costs. I just don’t like going period. And the office that I go to is like a pop-up office so I get upset each time I go, but I have to go so I go. I would rather go to a real office further out instead of in the “hood” but I don’t.”

In addition to the awareness of the diseases that cause ESRD, each of the participants provided their perceptions of accessibility to health care and the role health care access played in their current condition. The factors mentioned most often that could have impeded their decisions to seek health care, included long waits for minimal services such as prescription refills or blood pressure checks which were deemed of great importance but both were described as inconvenient and time consuming because they were required quite often. All participants were covered by health care insurance therefore none of the services they sought included any cost to them but transportation to and from the multiple appointments was a deterrent for several who described their fixed income as “strained” as a result of monthly visits. Participant 5 described her office visit experiences as draining because she has to pay a transportation service which will only take her so far then she has to take a different mode of transportation the rest of the distance and do the same on the way home. She explained that travel time for her to get to and from her appointments take hours and the doctor only spends about five minutes in the office with her after sitting in the lobby for up to two hours. She spent a considerable amount of time describing her experiences with access to health care because she sees multiple specialists and her appointments are scheduled on the two days that she does not have her dialysis treatments. She described her life as “always in some kind of doctor visit or dialysis; it’s all I do.”

One final and major finding was the fact that all participants expressed the desire to have a kidney transplant despite the inability to do so due to underlying health conditions and other issues preventing it. Each participant shared the same response when asked about other treatment plans considered besides dialysis. Each mentioned that a kidney transplant requires a lot of testing to get on the waiting list, weight loss in many cases, and a donor match. Most remain hopeful to one day make it happen to be able to get back to their old life before dialysis.

An analysis of the results and findings from this qualitative study answered the two research questions composed by the researcher to lead to the development of the strategy to execute delivery of better health outcomes for this population. The findings used to answer the two research questions were:

RQ1: What role does accessibility to care play in the lives of African Americans diagnosed with ESRD? All 10 participants had access to health care before and after their diagnosis of ESRD, each participant had health care insurance coverage before and after their diagnosis of ESRD, each participant went to a doctor's office for medical care and not the emergency room, and each participant attested to having a primary doctor and other specialists that provided their care.

RQ2: What factors influence the accessibility to care for African Americans diagnosed with ESRD? One participant reported that transportation issues and associated costs caused discomfort but did not cause participant to miss medical care. Two participants reported that long waits in the waiting area did not cause participant to miss medical care. One participant reported that repeat visits every month for prescription refills were inconvenient but did not cause participant to miss medical care. One participant exclaimed that a poorly equipped doctor office appearing like a "pop up" office instead of a more fully equipped office in another location further from home did not cause participant to miss medical care.

Prior to conducting the study, it was assumed that access to health care played a role in the fact that this population leads all other races with kidney disease. During the study, however, the participants explained that they have health care insurance along with no associated costs, had health care insurance prior to their ESRD diagnosis, and attended all doctor appointments. Therefore, access to health care, as defined as having the ability to receive the necessary medical care as well as health care insurance to pay for the care, did not play a role in the diagnosis of ESRD. Failure to understand the importance of adhering to the advice given by doctors, however, allowed their health conditions to worsen; more specifically, they made no changes to their lifestyle and activities that caused them to have diabetes and high blood pressure which are the two conditions that cause ESRD.

As discussed in Chapter 4, access to healthcare did not play a role, nor did any factors to access healthcare play a role in their condition. All 10 participants accepted responsibility for not responding to their diagnosis of diabetes and high blood pressure in a timely manner which could have made the difference between having kidney disease and turning their health condition around. Following a thorough analysis of the findings of the study, it was determined that access to health care coupled with understanding any medical care recommended and received, require the patient to take responsibility for making the necessary changes to avoid health conditions from worsening and for better health outcomes.

Lastly, all participants expressed the desire to advise non ESRD patients of the need to take care of their kidneys to avoid having to experience dialysis. Dialysis was described as “something they don’t tell us enough about.” The emphasis placed on this description lead researcher to believe that having knowledge of the dialysis process would be a deterrent and cause anyone to turn their life around to improve their health.

The majority indicated that they constantly remind their family members to do whatever they have to do to keep their kidneys healthy. One participant (Participant 6) strongly recommends that everyone have preventive services to monitor their overall health to allow the doctor to detect issues early and properly treat them. She further explained that had she spent more time having preventive services, she would not have ESRD today.

Limitations of the Study

Limitations of this qualitative research study include the small number of African American participants interviewed. In addition to the small number of participants is the fact that they were chosen from one dialysis facility. Future studies could include a larger number of participants from this population in various locations which may result in broader experiences with this condition.

Recommendations

According to African American participants with ESRD, it is recommended that the provider community spend more time on patient education on the diseases that lead to ESRD including a more in depth breakdown of the exact harm the diseases can cause to the kidney and other organs. It is highly recommended that providing a detailed account of what happens when the kidneys fail to function to capacity including what to expect from dialysis treatments as a life sustaining measure would be the most realistic preparation or method of avoidance according to the majority of the participants. The participants described feelings of unpreparedness for such a life changing process and indicated that had they known they would have done all that they could to avoid dialysis.

African Americans also lead all other ethnic groups with diabetes and high blood pressure which cause ESRD therefore educational programs to teach this population about the causes of these diseases, could eliminate the increasing cases of diabetes and high blood pressure. A gap in the literature is reflected by the availability of only quantitative research and no qualitative studies to answer the question of why; why are these conditions that lead to ESRD so prevalent among this population. Additional qualitative research is also recommended in the form of a focus group of patients and the provider community. This would allow for a diverse, open and honest exchange of ideas, opinions, and stronger relationships between patients and their providers built on trust while together creating educational forums to combat the constant rise in the diagnoses that lead to this and other terminal conditions.

Implications for Positive Social Change

Creation of a strategic plan to improve health literacy and communication between patients of this population and the provider community would have implications for positive social change because it would help this population build trust in the health care system, help reduce the increasing morbidity and mortality associated with this condition as well as eliminate health inequities. Given that each participant expressed the strong desire to help others to avoid the need for dialysis, an educational program or policy shared by community leaders and the primary care physician during a preventive office visit to introduce this population to the kidney, its function and importance, what actions and health conditions harm it, and a thorough description of the dialysis process including a video, would help educate patients on the prevention of the conditions that lead to ESRD. This educational program could be shared in schools, libraries, and churches to reach more of the community and follow up communications can be had during office visits with the primary care physicians.

Repetition of important health reminders and educational documentation found in multiple locations throughout the community, should help spread awareness. Future qualitative research conducted with a focus group specifically composed of diabetic, pre diabetic, ESRD patients, providers caring for these patients, and other leaders of the African American community should also allow for an opportunity to have open communication and spread awareness based on the diverse make-up of the focus group.

Conclusion

The intent of the qualitative research conducted in this study was to determine if use of health services and factors they shared played a role in the African American population constantly rising cases of ESRD. Participants sought medical care despite a) having a poor understanding of the importance of making necessary lifestyle changes to avoid conditions that cause ESRD from worsening, b) having limited knowledge on the expectations and requirements resulting from the ESRD diagnosis, c) having no knowledge of the dialysis process and feeling blindsided as a result, and d) having medical visits and multiple lengthy dialysis treatments every other day. These findings represent an accurate account of the concerns or experiences of this small number of African Americans. Barriers such as lack of trust of the provider and the health care system as a whole, were barriers that could deter members from seeking care but these participants remained committed.

Utilization of health care services was the framework and foundation of this study. Predisposing, enabling, and need factors were proven by the perceptions shared by the participants. Attitude towards the health care system, how to access health care, and wait times were factors mentioned during the interviews that mirrored the predisposing, enabling, and need factors defined in the utilization of health services framework. Contrary to the factors detailed in this framework are other factors such as inadequate time spent listening to patients and insufficiently explaining treatments. These factors were also experiences and perceptions described in the interviews.

Literature shows that several quantitative research studies have been conducted on the African American population with ESRD. Those quantitative studies also reflect the fact that African Americans lead all ethnic groups in the conditions that cause ESRD. The findings from this study reflect that 100% of participants suffer from diabetes and hypertension which are the conditions that cause ESRD. Focusing on the experiences of this small group of participants, their desire to learn more about their condition to help others to avoid becoming another statistic, and their perceptions of health care access and expectations of good service, it can be concluded that more qualitative research should be conducted to gain a deeper understanding of the needs of the African American population as a whole to avoid the constant rise in this condition and all other conditions evidenced by the health disparities that currently exist.

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Appendix A: Interview Questions

Do you have any questions for me before we begin?

- Tell me a little about yourself.
- When you seek medical care, do you go to a doctor's office or another treatment facility?
    - Please explain how you decide where to seek medical care.
    - What are some of the reasons you seek medical care there?
    - What are some reasons (if) you don't seek medical care in other places?
    - How often do you seek medical care?
    - Please explain how often you seek medical care now that you have this condition. More often or less often than before? Why?
    - What are some reasons that make you avoid seeking medical care?
    - How far do you travel for medical care?