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The Experiences of Obese African American Women and Their Utilization of Preventive Healthcare Services

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ACCEPTANCE

This dissertation, THE EXPERIENCES OF OBESE AFRICAN AMERICAN WOMEN AND THEIR UTILIZATION OF PREVENTIVE HEALTHCARE SERVICES by Winsome Stephenson was prepared under the direction of the candidate's dissertation committee. It is accepted by the committee members in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing in the Byrdine F. Lewis School of Nursing in the College of Health and Human Sciences, Georgia State University.

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ABSTRACT

THE EXPERIENCES OF OBESE AFRICAN AMERICAN WOMEN AND THEIR UTILIZATION OF PREVENTIVE HEALTHCARE SERVICES

by

WINSOME STEPHENSON

Obesity is associated with higher death rates from breast and gynecological cancers. African American women (AAW) are more likely to be diagnosed with these cancers at later stages (Cui et al., 2003) and have lower survival rates than Caucasian women (Stolley, Sharpe, & Schieffer, 2009). African American women are also disproportionately affected by obesity. Studies suggest that the healthcare experiences of obese women (primarily stigmatization), may contribute to their utilization of preventive healthcare services (Howe 2006; Vallis Currie, Lawlor, & Ransom, 2007). However, these studies have largely comprised Caucasian women; there remains a paucity of studies addressing this issue in AAW. The purpose of this study was to explore the healthcare experiences of AAW and their utilization of preventive healthcare services.

Interpretive phenomenology, based on the work of Max van Manen, was used to describe and interpret the healthcare experiences of 15 obese AAW, living in communities in Georgia. The women ranged in age from 23 to 62 with BMIs ranging from 35-55. The majority of the sample (83%) had adequate health insurance. This was a well educated sample with 87% having college degrees or some college education. Individual, audio-taped interviews were used to collect data.

Data were analyzed using interpretive phenomenological methods, with analysis and collection occurring concurrently. Data were analyzed as a whole then line by line

for themes across transcripts. Two patterns and five major themes were identified. Patterns were: They're not listening and Good or bad, it's my decision. Themes were: Attributing all problems to weight; They say lose weight but give us no tools; Stigmatization; Cancel my appointment please: I won't be back, and Empowerment.

The women recalled a plethora of negative encounters with providers that they termed demeaning, and "nastiness for no reason." Many women reacted by delaying or avoiding healthcare, some not returning for preventive health screens for several years. The significant association between obesity and mortality from cervical and breast cancers necessitates timely preventive screens by obese women. The results of this study can help to inform practice, education, and research. Recommendations for all three areas were delineated in this study.

THE EXPERIENCES OF OBESE AFRICAN AMERICAN WOMEN AND THEIR UTILIZATION OF PREVENTIVE HEALTHCARE SERVICES

by

WINSOME STEPHENSON

A DISSERTATION

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TABLE OF CONTENTS

Section Page

List of Figures xv

List of Abbreviations xvi

Chapter

I. INTRODUCTION 1

Background 1

Statement of the Problem 7

Purpose Statement 11

Significance of Study to Nursing 12

Research Questions 12

Definition of Terms 13

Summary 14

II. LITERATURE REVIEW 16

Healthcare Utilization 16

Obesity Stigmatization 19

Stigmatization in Healthcare: Perspectives of Obese Persons 21

Stigmatization in Healthcare: Perspectives of Health Care Providers 23

Stigmatization and Healthcare Utilization 28

Assumptions 31

Interaction Model 33

Summary 33

III. METHODOLOGY 36

Chapter Page

Design 36

Sample 38

Recruitment of Participants 38

Data Collection 40

Data Analysis 42

Authenticity and Trustworthiness 43

Protection of Human Subjects 45

Ethical Considerations 45

Minorities 46

Summary 47

IV. RESEARCH PROCESS 48

Recruitment 48

Data Generation: Initial Interviews 49

Data Generation: Follow-up Interviews 52

Data Analysis 54

Trustworthiness 55

Summary 56

V. FINDINGS AND DISCUSSION 57

Demographic Profile 57

Patterns and Themes 58

Pattern#1: They're not Listening 58

Chapter Page

Theme#1: Attributing All Problems to Weight 58

Theme#2: They Say Lose Weight but Give Us No Tools 64

Theme#3: Stigmatization 68

Pattern#2: Good or Bad: It's My Decision 83

Theme#1: Cancel My Appointment Please: I Won't Be Back 83

Theme#2: Empowerment 90

Discussion 98

Race, Gender and Stigmatization 99

Stigmatization: General 99

Stigmatization: Environmental Inadequacies 102

Stigmatization: Provider Characteristics 103

Delaying Care 105

Not Listening: Blaming Weight 109

Empowerment: Knowing Risks and Consequences 110

Study Limitations 113

Summary 114

VI. CONCLUSIONS AND RECOMMENDATIONS 115

Implications for Clinical Practice, Education, Policy, and Research 116

Summary 118

REFERENCES 121

APPENDICES 147

Appendix A: Institutional Review Board Approval-Georgia State University 148

Appendix B: Institutional Review Board Approval-Mercer University..... 150

Appendix C: Consent Form 152

Appendix D: Recruitment Flyer..... 156

LIST OF FIGURES

Figure Page

1. Interaction Model of Client Health Behavior 33

LIST OF ABBREVIATIONS

AA	African Americans
AHRQ	Agency for Healthcare Quality and Research
AAW	African American Women
BMI	Body Mass Index
BRFSS	Behavioral Risk Surveillance System Surveys
CDC	Centers for Disease Control
DHHS-OWH	Department of Health and Human Services-Office of Women's Health
DNPAO	Division of Nutrition, Physical Activity and Obesity
HCP	Health Care Provider
IAT	Implicit Association Test
IMCHB	Interaction Model of Client Health Behavior
MEPS	Medical Expenditure Panel Survey
MIDUS	Midlife Development in the US
MMWR	Morbidity and Mortality Weekly Report
NCHS	National Center for Health Statistics
PCI	Percutaneous Coronary Interventions
WHO	World Health Organization

CHAPTER I

Introduction

Background

Obesity has become a major national and international problem. Globally, about five hundred million persons are classified as clinically obese (World Health Organization [WHO], 2011) and in the United States, the number of obese persons exceeds seventy- two million (National Center for Health Statistics [NCHS], 2007). Obesity rates have not decreased in the last 30 years; in fact, obesity prevalence has more than doubled in that time span, from 15% to the current 34% (Centers for Disease Control and Prevention [CDC], 2009).

Even though the problem of obesity crosses genders and ethnicities, the rate is highest in women and African American women (AAW) are affected disproportionately (James, Fowler-Brown, Raghunathan, & Van Hoewyk, 2006; U.S. Department of Health and Human Services: The Office of Minority Health, 2007). Studies show that in 2007-2008 women in the United States had an obesity prevalence rate of 35.5% while the rate for men was 32.2% (Flegal, Carroll, Ogden, & Curtin, 2010). By the year 2020, it is projected that 43.3% of women in the United States population compared to 40.2% of men will be obese (Ruhm, 2007). Furthermore, at higher obesity levels (Body Mass Index [BMI] >35), estimates show that women in the United States will have a

disproportionately higher rate than men, at 43% and 25% respectively (Ruhm, 2007). For African American women, four out of every five are either obese or overweight and they are almost twice as likely to be obese as Caucasian women (CDC-Morbidity and Mortality Weekly Report [MMWR], 2009; James et al., 2006; US Department of Health and Human Services: The Office of Minority Health, 2007; Sbrocco et al., 2005). Data from the Behavioral Risk Factor Surveillance System surveys (BRFSS), collected in 2006-2008, showed that African American women had an obesity prevalence rate of (39%), compared to White American women who had the lowest rate at 21.8% (CDC-MMWR, 2009).

Some may argue that AAW are more comfortable with their weights and are more accepting of larger body sizes (Baturka, Hornsby & Schorling, 2000; Breitkopf, Littleton, & Berenson, 2007; DiGioacchino, Sargent, & Topping, 2001; Dutton, Martin, & Brantley, 2004; Grabe & Hyde, 2006; Hawkins, Tuff & Dudley, 2006; Kumaniyika, 1994). However, in spite of the inclination for some AAW to be self accepting of their weights, studies show that many AAW who are overweight are frequently dissatisfied with their weights (Abrams, Allen & Gray, 1993; Ard, Greene, Malpede, & Jefferson, 2007; Boyington, Johnson, & Carter-Edwards, 2006; Tyler, Johnston, Dalton, & Foreyt, 2009). Regardless of the perception that this group of women has of their weights, the prevalence of obesity in this population is unmistakable and the consequences are deleterious.

Health consequences attributed to obesity affect the obese individual on all spheres of life, physiological, psychological and sociological (Carr & Friedman, 2005;

Jenkins 2004). Some physiological consequences of being obese are potentially fatal to the obese woman but with timely and preventative health screens, the woman may be spared the debilitating or fatal outcomes of these conditions. Research shows that obese women are particularly vulnerable to breast, cervical and endometrial cancers (Cohen et al., 2008; Hu, 2003; Lane, 2005; Lahmann et al., 2004; Ludman et al., 2010; Maruthur, Bolen, Brancati, & Clark, 2009; Steiner, Klubert, & Knutson, 2008) and are at increased risk of dying from these cancers (Maruthur et al., 2009; Modesitt & van Nagell, 2005). Unlike other health conditions (i.e., heart disease, respiratory illness, etc.), breast and gynecological cancers can be detected at early onset and can benefit from early treatment. A large prospective study, which examined 495,000 overweight and obese women over a 16 year period, found that women with higher BMIs (at least 40) had death rates from all cancers that were 65% higher than women of normal weight (Calle, Rodriquez, Walker-Thurmond, & Thun, 2003). Additionally, BMI was significantly associated with higher rates of death from breast, cervical, uterine and ovarian cancers (Calle et al., 2003), deaths that could possibly have been prevented with early screens and treatment. African American women, the group most affected by obesity, have a greater likelihood of being diagnosed with breast cancer at later stages, after the disease has already metastasized (Cui et al., 2002). In addition, AAW have lower survival rates from breast cancer than do White women (Stolley, Sharpe, & Schieffer, 2009).

A mammogram is the single most effective method to detecting breast cancer at an early stage (American Cancer Society, 2007); however, research suggests that even with the increased risk of the disease that obese women have, they delay utilizing

healthcare services for preventative screens for breast and other gynecological cancers (Amy, Aalborg, Lyons & Keranen, 2006; Fair et al., 2009). Wee, McCarty, Davis, & Phillips (2000), in a study of over 11,000 women , found that in the 18-75 age groups, only 78% of obese and overweight women who had not had hysterectomies reported having a Pap smear in the 3 years preceding the survey, compared to 84% of normal weight women. At older ages (50-75), only 62% and 64% of obese and overweight women respectively, had Pap screens in the preceding 2 years. Rosen & Schneider (2004) had similar findings. Of 53,000 women studied, the authors found that those who were morbidly obese had a 6% less likelihood of being screened for colorectal cancer. It is reported that even when adequate insurance is not an issue, obese women delay seeking health screens because of their weights (Fontaine, Moonseong, & Allison, 2001).

Findings examining the issue have been somewhat inconsistent. Some researchers have suggested that obesity is a barrier to cancer screens in White women but not in AAW (Ostbyte, Taylor, Yancy & Krause, 2005; Wee, Phillips, & McCarthy, 2005). Others have reported that there is a more consistent relationship between decreased screens for cervical cancer and increased body size in White women than in AAW. Still, some have suggested that there is decreased screening for breast cancer among White women but not among Black women (Cohen et al., 2008). However, Ferrante, Chen, & Jacobs (2006) found that black women are less likely to be up to date with their mammography screens (51.3%) than White (62.5%) and Hispanic (84.8%) women. For papanicolau screens, AAW were also found to be less likely to be screened than White and Hispanic women with 72.7% and 82.1% respectively. The study had 1809

participants (Hispanics = 878, Blacks = 632). There were 427 obese Hispanic and 375 obese Black women in the study.

Other physical consequences that are attributable to obesity have been explicated in the literature. Obese persons experience cardiac problems at an earlier age. In a study of 1,631 patients who had percutaneous coronary interventions (PCI), it was found that at the time of the surgery, obese patients were significantly younger than normal weight patients (Poston, Haddock, Conrad, & Spertus, 2004). In addition, the negative impact of obesity on diabetes (Hossain, Kawar & Nahas, 2007; Rodbard, Fox, & Grandy, 2009; Wang, McDonald, Reffitt & Edington; 2005; Wilborn et al., 2005), and respiratory illness (Chlif, Keochkerian, Choquet,Vaidie, & Ahmaidi, 2009; Lederer et al., 2009; Ora, Laveneziana, Ofir, Deesomchuk, Webb, & O'Donnell, 2009) have been elucidated in the literature. Decreased quality of life has also been attributed to obesity (CDC-MMWR, 2009; Wilborn et al., 2005). In examining the relationship between obesity and health related quality of life, Jia & Lubetkin (2005) examined data from the 2000 Medical Expenditure Panel Survey (MEPS) for over 13,000 adults and found that persons who were obese had significantly lower health related quality of life than persons who had normal weights.

The psychological consequences of obesity have also been reported (Becker, Margraf, Turke, Soeder & Naimer, 2001; Bookwala & Boyar, 2008; Chwastiak et al., 2009; Hach, 2007; Kivimaki et al., 2009). In a study of 509 participants it was found that obese persons had higher incidences of depression (Bertakis & Azari, 2005). Another study reported a negative relationship between self-esteem and BMI such that, as BMI of

the participants increased, their self-esteem decreased (Bodiba, Madu, Ezeokana & Nnedum, 2008). Obesity also has implications for one's socioeconomic status (McLaren, 2007; Morris, 2006; Rodriquez, Martinez, Novalbos & Escobar, 2008; Tunceli, 2006). A negative relationship was found between SES and obesity (Brennan, Henry, Nicholson, Kotowicz, & Pasco, 2009; Sing, Kogan, Van Dyck & Siahpush, 2008). With the magnitude of consequences, obesity presents a significant financial burden for society. Current data shows that the annual healthcare costs associated with obesity may have been as high as 147 billion dollars in 2008 (Finkelstein, Trogden, Cohen & Dietz, 2009). Additionally, obesity accounts for more than eight percent of the total Medicare expenditure and eleven percent of Medicaid expenditure (Finkelstein et al., 2009). The dramatic increase in the rate and consequences of obesity has sparked intensified efforts from various sectors to decrease the burden associated with the condition.

The CDC's Division of Nutrition, Physical Activity, and Obesity (DNPAO) provides funds to many states to help in initiation of programs aimed at alleviating obesity, particularly childhood obesity. Such programs include increasing physical activity, decreasing time spent watching television, decreasing intake of sugar sweetened beverages and increasing consumption of fruits and vegetables (CDC, 2011). Recently, one million dollars was awarded to U S states and territories to help them in their efforts to reduce obesity (CDC, 2011). In addition, The First Lady's popular "Let's Move" initiative was recently started, aimed at combating childhood obesity. Further, since 2003, the Agency for Healthcare Quality and Research (AHRQ) has committed almost $2.8 million in support of obesity research (AHRQ, 2006). However, the problem

continues to be exacerbated, especially in AAW. Additionally, the goal of Healthy People 2010 to decrease the prevalence of obesity to 15% by 2010, Healthy People (2010), was not attained; in fact, as discussed earlier, the prevalence of obesity has more than doubled since the inception of that goal and the consequences of the condition have also spiraled. Therefore, public measures to prevent obesity and its detrimental consequences have largely failed.

Statement of the Problem

In this section I present data that shows a connection between stigma and healthcare utilization. Findings from several qualitative studies will be presented. The data will consistently show that obese women are stigmatized in healthcare settings and that their experiences contribute to the decisions to delay use of healthcare services.

As indicated earlier, obese AAW have disproportionately high rates of obesity and suffer the major consequences of the disease but do not readily utilize healthcare services for preventive care. These facts predispose obese AAW to breast and gynecological cancers. Researchers have speculated as to possible reasons for the delay in healthcare utilization for preventive health screens by obese women. With the myriad of psychological, physical and sociological problems to which obese persons are prone, there may be any number of factors influencing the obese woman's utilization of preventative healthcare services. However, the literature clearly elucidates stigmatization of obese persons by healthcare providers and points to stigmatization as a possible hindrance to healthcare utilization in this population of women (Fontaine, Faith, Allison & Cheskin, 1998; Howe, 2006; Vallis et al., 2007; Zuzelo & Seminara, 2006).

Healthcare providers (HCP) have reported harboring negative attitudes toward obese people and obese women have described stigmatizing encounters while utilizing health care services (Berryman, Dubale, Manchester, & Mittelstaedt, 2006: Carr & Friedman, 2005; Foster et al.; 2003; Hoppe & Ogden 1997; Howe, 2006; Jeffrey & Kitto, 2006; Martyn-Nemeth, Penckofer, Gulanick, Velsor-Friedrich, & Bryant, 2009; Olson, Schumaker, & Yawn, 1994; Puhl, Moss-Racusin, Schwartz, & Brownell, 2007; Vallis et al., 2007). Furthermore, obese women have reported delaying cancer screening tests because they perceive negative treatment from healthcare providers because of their weights (Amy et al., 2006).

For example, in a survey that examined the attitudes of physicians toward obesity and its treatment (n=620), more than 50% of the physicians surveyed considered patients who were obese to be awkward, unattractive and non-compliant (Foster et al., 2003). Similarly, in a study of 399 physicians, 40% reported having negative reactions toward obese patients (Jay et al., 2009). Moreover, in Hebl & Xu, (2001), physicians admitted to spending less time with obese patients and perceiving them in a significantly more negative manner than non-obese patients. Poon & Tarrant (2009) had similar findings. They investigated the attitudes towards obese persons of 198 registered nurses and found that registered nurses had high levels of "fear of obesity." Obese persons were perceived as overeaters, shapeless, slow, unattractive and liking food. Earlier studies also had similar findings (Bagley et al., 1998; Maroney & Golub, 1992).

Carr & Friedman (2005) reported that obese persons with BMIs greater than 30 perceived that they were discriminated from various sources and that they were

stigmatized because of their excess weight. Further, participants who had the highest BMIs reported that along with discrimination from the general public, they also perceived discrimination from health care providers. Pryor (2002) argued that persons who were obese were afraid to approach health practitioners and go to health facilities primarily because of encountering disapproving and discriminatory attitudes regarding the fact that they were obese.

Obese women have reported delaying cancer screening tests because they perceive their weights to be problematic to HCPs (Amy et al., 2006). Studies have found a positive relationship between increasing BMI and reports of care seeking delay (Adams, Smith, Wilbur, & Grady 1993; Amy et al., 2006; Drury & Louis, 2002; Olson et al., 1994). For example, Adams et al. (1993) found that women with higher BMIs were more reluctant to have pelvic examinations. Similarly, Amy et al. (2006) reported that African American and Caucasian women (n=498) with BMIs greater than 25 had lower rates of PAP tests (68%) than non-obese women (86%). Ninety (90) percent of this sample had adequate insurance, again contradicting the belief that adequate health insurance is the primary hindrance to care for obese women. Barriers reported for the delay were disrespectful treatment and negative attitudes of HCP, embarrassment at being weighed, and being told to lose weight when their visit was not related to their weights. In addition, women delayed healthcare because they did not want a "lecture" from the HCP regarding their weight (Olsen et al., 1994).

Along with the reported barriers to care, a possible contributing factor to the women's delay was the report that some physicians (17%) were reluctant to perform

pelvic exams on obese women, while others (83%) indicated that they were unwilling to perform these exams on women who were reluctant to have them. These data attest to the fact that obese AAW may suffer the consequences of delayed screens for preventable cancers if they perceive stigmatization and discriminatory attitudes from HCPs when they attempt to utilize healthcare services.

Even though a high BMI results in greater utilization of healthcare services (Zizza, Herring, Stevens, & Popkin, 2004) and greater healthcare costs (Wolf et al., 2008), utilization is primarily for unavoidable care and not for preventive care (Fontaine & Bartlett, 2000). For example, in the United States and several other countries, it was found that obese persons had greater utilization costs because of longer hospital stays and greater prescription drug use; utilization was related to treatment for obesity related illnesses and not for use of preventative services (Barrett, Colosia, Boye, & Oyelow, 2008). Wolf et al. (2008), in a study (n=1167) of predominantly Caucasian participants, found that the highest healthcare resource utilization was for prescription medications to treat conditions related to the health consequences of obesity, specifically, diabetes, hypertension, hypercholesterolemia, and depression. Others have had similar findings (Raebel et al., 2004). It is apparent that preventative healthcare services are not readily accessed by obese persons (Brownell, Schwartz, Puhl, & Rudd, 2005); healthcare utilization at the time when health consequences of obesity have manifested themselves is counter to what would be most beneficial for the obese woman who is at risk for the preventable diseases discussed. Instead of this "down-stream" approach, a more "up-stream" approach is needed where obese women are seek health screens for preventable

diseases and do not wait until the diseases have occurred to treat them. This "up-stream" approach may be less costly in terms of burden to the obese individual and the economy. In addition, it may increase the woman's quality of life.

To impact the frequency with which obese AAW utilize preventative healthcare services to obtain screens for breast and gynecological cancers, the perspectives of this group of women regarding the issue must be known. Several facts are already known regarding the issue. First, findings show that stigmatization of obese women exists in healthcare settings. Second, stigmatization impacts health-seeking habits of obese women. Last, there are few recent studies addressing the phenomenon. Missing from the body of knowledge regarding this issue is the voice of AAW. There is poor representation of AAW, the group most affected by obesity, in the studies. No study has reported findings from this population exclusively; therefore, the voices of this sector in society are silent on the issue. Additional research studies on the phenomenon need to therefore focus on exploring the lived experiences of obese AAW, their perspectives on healthcare utilization for preventative health screens and reasons that impact their delayed utilization of such services. Additional research studies will also fill the gap created by the lack of recent research data on the phenomenon.

Purpose Statement

The purpose of this qualitative, hermeneutic phenomenological study was to explore the experiences of obese AAW as they utilize healthcare services and understand the decisions they make to utilize preventive healthcare for mammograms and Pap screens based on their experiences.

Significance of Study to Nursing

This study is significant in that, learning the stories of obese AAW as they have utilized the healthcare system, and gaining insight into the experiences that may influence their use of preventative health care, may guide researchers into understanding the behaviors that impact avoidance or utilization of healthcare services in AAW and may help nurses tailor nursing their interactions with obese persons to incorporate obesity sensitive care. The knowledge gained from this study may provide the information needed to develop interventions aimed at promoting timely use of preventative healthcare services by AAW, with an ultimate goal of reducing mortality from breast and gynecological cancers in this at risk population.

Research Questions

The following research questions guided the research process:

RQ1: What general experiences do obese African American women have while utilizing healthcare services?

RQ2: What negative experiences, if any, do AAW have with healthcare providers and how do these encounters influence their decisions to utilize preventative healthcare services?

To guide participants into initiation of the interview, the following interview questions were asked: "Tell me about your general experiences (positive and negative) using healthcare services," and "Tell me about your experiences using healthcare for preventative health services" (i.e., breast and gynecological screens). As the interview

evolved, other probing and clarifying questions were asked as was deemed necessary, to ensure that the participants' stories were told and understood completely.

Definition of Terms

Definition of terms refers to words that are frequently used in this study. Definitions are offered for clarification.

Body mass index (BMI) provides a reasonable indicator of a person's body fat. It is calculated using the following formula: Weight in pounds divided by height in inches squared and multiply by 703. (Wt (lbs) / ht (inches)^2 x 703) (CDC, 2011).

Morbid obesity refers to a body mass index that is equal to or greater than 40 (CDC, 2011).

Obesity is defined as a body mass index that is equal to or greater than 30 (CDC, 2011).

Overweight is defined as having a body mass index of 25 to 29.9.

Normal weight is considered to be a body mass index of 18.5 to 24.9.

African American women (AAW) refer to self-identified Black women of African ancestry.

Prevalence refers to the number of persons in a population with a disease at a given time.

Obesity prevalence refers to the number of persons who are obese in a population currently.

Anti-fat bias refers to the existing negative attitudes directed at persons who are perceived to have excess weight. This bias frequently results in discriminatory acts.

Obesity stigma is defined as the social disapproval associated with the stereotypes of anti fat biases.

Health care provider/practitioner (HCP) refers to all professionals who work in any area of the healthcare system and provide any type of healthcare service to persons.

Health care setting/system refers to any entity where trained healthcare professionals provide health care for persons. These include, but are not limited to, hospitals, physicians' offices (all specialties), health clinics, dental offices, etc.

Preventative healthcare service for this study is specifically defined as health that the woman seeks to detect breast and gynecological cancers. These are mammograms and papanicolau tests.

"Down-stream" approach is a public health methodology pertaining to the treatment of a health problem after it has occurred instead of using measures to prevent the occurrence of the problem.

"Up-stream" approach is a public health methodology that uses measure of prevention to prevent health conditions before they occur.

Summary

In summary, obesity is a major health crisis that contributes significantly to multiple health problems. Several facts were presented in this discussion. First, AAW have disproportionately high rates of obesity. Second, obesity is a significant risk factor for breast and gynecological cancers in women. Third, AAW are diagnosed with breast cancer at later stages and die from the disease at higher rates than do Caucasian women. Fourth, obese women have reported negative encounters while interacting with healthcare

providers and last, obese women delay utilizing healthcare services for screens that would provide early detection of these potentially fatal conditions.

If the disproportionately high obesity rate that is currently evidenced in women increases, as the data suggests it might (Ruhm, 2007), it is not difficult to envision that the high risk for breast and gynecological cancers will also increase exponentially. Research that elicits AAW's accounts of meaning, experiences and perceptions regarding utilizing healthcare services for preventative screens must be conducted. This can best be achieved with qualitative research. Qualitative research focuses on understanding AAW's experiences, told in their own voices; therefore, it is the appropriate methodology for this particular study. Examining healthcare utilization qualitatively allows the researcher to gain insight into the "first hand" experiences of AAW and provides a medium where this population of women can address experiences and reasons for delay or timely use of preventative healthcare services.

CHAPTER II

Literature Review

I begin this chapter by discussing utilization of healthcare services as the phenomenon has been widely measured in obese persons; I also briefly highlight how healthcare utilization has been measured in other health conditions. Next, a general discussion of obesity stigma as it exists in society is given. I then elaborate on obesity stigmatization from the perspective of obese persons as well as healthcare providers. Finally, I conclude the chapter by elucidating the influence of obesity stigmatization on healthcare utilization.

Healthcare Utilization

Even though healthcare utilization by obese persons has been examined in the literature (Andreyeva, Sturm, & Ringel, 2004; Encinosa, Bernard, Chen & Steiner, 2006; Holl, Almagor, Dick, & Dunlop, 2001; Peytremann-Bridevaux & Santos-Eiggimann, 2007; Wang et al.; 2005; Wolf et al., 2008), the studies have focused on the utilization of healthcare services primarily from a quantitative perspective, reporting on types of health services people are seeking, to what degree they are using these services and who is utilizing the services (Bernstein, Hing, Moss, Allen, Sillar, & Tiggle, 2003). Studies examining healthcare utilization from a qualitative perspective are either sparse or outdated (Amy et al., 2006; Drury & Louis, 2002; Fair et al., 2008; Howe, 2006; Olson, et al., 1994; Wee et al., 2000). Furthermore, there are few qualitative studies examining

healthcare utilization by obese AAW (Lynch, Chang, Ford, & Ibrahim, 2007), a gap that this study proposes to fill. There is no consensus in the literature as to the exact definition of healthcare utilization by obese persons and how utilization is to be measured. For example, in a sample of overweight and obese adults, Peytremann-Bridevaux & Santos-Eggimann (2007) measured healthcare utilization, defining it based on ambulatory care service, visits to general practitioners and specialists, number of times hospitalized and nights spent in hospital, surgeries had, and home care, all received in a 12 month period. On the other hand, Wang et al. (2005) examined the relationship between BMI and healthcare utilization among Medicare retirees and defined healthcare utilization as the number of emergency room visits, days hospitalized, inpatient and outpatient costs and costs for pharmacology that occurred in a two year time span. In contrast, Encinosa et al. (2006) defined healthcare utilization, in a sample of bariatric surgery patients, by the number of health care claims received in the six month period after the participants had bariatric surgeries.

Others have examined healthcare utilization in various other health conditions and even though aspects of measurement have been similar in these studies, as with obesity, consensus of measurement has been lacking. In cardiovascular disease, healthcare utilization has been defined as visits to: (a) a family physician (b) a nurse practitioner, (c) a cardiac surgeon, (d) an emergency department, (e) other providers, including chiropractors and naturopaths, as well as re-admissions to a hospital, all occurring within at 12 month time frame (Routledge et al., 2009). Number of cardiac prescriptions filled has also been used as a determining factor for utilization in patients with cardiovascular

problems (Beaton et al., 2009). Cancer related healthcare visits, defined as visits that are expected because of an individual's cancer diagnosis, and preventable healthcare service, defined as visits that are unrelated to an individual's cancer diagnosis, all measured over a time period of six months, have also been used to capture healthcare utilization in patients with cancer (Chumbler et al., 2007).

Measurement of hospitalization days, visits to specialists and emergency departments and number of prescriptions given to patients, measured for a five year period prior to the diagnosis of sleep apnea, have all been employed as specific definitions of healthcare utilization for sleep apnea (Greenburg-Dotan, Reuveni, Simon-Tuval, Oksenburg, & Tarasiuk, 2007). In addition, respiratory medication use, 12 months before and 24 months after treatment, has been used to measure usage of healthcare services in persons with chronic obstructive pulmonary disease (Joo, Lee, Bartle, Graaff, & Weiss, 2008; Yu-Isenberg, Vanderplas, Chang & Shah, 2005). Others measuring healthcare utilization by patients with chronic pain have used frequency of home care nurse visits in a six month period (Hollisaaz et al., 2007) and number of visits to a pain clinic (Blyth, March, Brnabic, & Cousins, 2004). Healthcare utilization for patients with diabetes has been defined as visits for laboratory and diagnostic procedures that are either specifically related to diabetes or related to other causes (Nair, Miller, Park, Allen, Saseen, & Biddle, 2009; Shenolikar & Balkrishnan, 2008).

Most of the studies focus primarily on the types of healthcare services being used and financial costs related to the service, and not on reasons the services are being used. Thus, there is a need for additional qualitative studies in this population of women. In

addition, most of the studies examine healthcare utilization for services related to chronic health care and treatment for existing diseases; they do not examine utilization for preventative healthcare use. Even though this study does not propose to measure healthcare utilization quantitatively, it is important to delineate a definition of how healthcare utilization will be perceived in the study. Therefore, healthcare utilization for this study is defined as a visit to any health care provider, for preventative health care. The focus of this definition is based on the stories that obese AAW tell regarding their decisions to utilize or avoid healthcare.

It is clear that obese persons encounter stigmatization by HCPs and do not utilize healthcare services as readily for preventive health screens as they do for treatment of diseases that arise as a result of obesity. With the lack of representation of AAW in studies examining the issue, there remains a large gap in the knowledge regarding the issue from the AAW's perspective.

Obesity Stigmatization

Weight bias in American society is pervasive, affecting every aspect of existence (Puhl & Heuer, 2009). Because a thin body figure is seen in the American culture as normal, acceptable and beautiful, women are pressured to maintain the thin ideal (Hebl, King & Perkins, 2009). Individuals who do not measure up to this image are perceived as "different" and are often times stigmatized. Negative social judgment aimed at persons who are obese is now considered the norm in the American society (Friedlander, Larkin, Rosen, Palermo & Redline, 2003; Hebl & Mannix, 2003) and it is reported that society reacts to obese individuals as if they were harboring some type of disease

(Klaczynski, 2008). Stigmatized individuals are usually assigned certain deviant labels that cause them to be treated unfairly and to experience discrimination (Puhl et al., 2007). Puhl & Brownell (2001, 2003) suggested that the final acceptable targets of discrimination in society are obese persons and this stigma is powerful and quite difficult to transform.

Stigma is not a new phenomenon; it is ageless. In his classic work on stigma (Goffman, 1963, p. 3) defined stigma as "an attribute that is deeply discrediting." He further writes that the stigmatized individual is "reduced in our minds from a whole and usual person to a tainted, discounted one" (p. 3). Stigma is further defined as something that denotes a negative connotation, a mark of shame or discredit, a moral or physical blemish and a prominent personal trait that can be perceived as socially, physically, or psychologically disadvantageous (The American Heritage Medical Dictionary, 2004; McGraw Hill Concise Dictionary of Modern Medicine, 2002; Mosby's Medical Dictionary, 2008). Stigmatization of persons who are obese is also an enduring phenomenon. Social scientists started to recognize the effects of obesity stigmatization many years before obesity was considered a major health crisis. For example, Cahnman (1968) suggested that obese individuals are more susceptible to discrimination than persons of other marginalized groups. He defined stigmatization as "…rejection and disgrace that are connected with what is viewed as physical deformity and behavioral aberration" (p. 293). Similarly, Maddox, Beck, & Liederman (1968) suggested that people's evaluation of the obese individual as well as the individual's perception of him or herself, are frequently negatively influenced by the individual's excess weight.

Weight stigmatization has dangerous consequences (Swami et al., 2008) and for persons who are obese, stigmatization has negative effects on every dimension of their lives (Myers & Rosen, 1999).

Of particular importance to this discussion is the estimate that obesity discrimination in the United States has seen an increase from 7% in 1995-1996 to 12% in 2004-2006 (Andreyeva, Puhl & Brownell, 2008). This finding was from The National Survey of Midlife Development in the US (MIDUS), a survey of English speaking community adults. The authors attribute this increase to the escalating obesity prevalence. A clarification of this statement was not offered by the authors; however, one explanation may be the fact that the increased numbers of obese persons have generated increased intolerance of obesity by persons who have the tendency to stigmatize the condition. This is particularly troubling data because it highlights the fact that the stigmatization of obese persons has not benefited from the policies and laws enacted in this country over the years that prevent such biases as racism or sexism. Obese persons have been perceived as visually displeasing, socially handicapped, aesthetically displeasing, and morally impaired (Allon, 1982; Cahnman, 1968; Crandall & Biernat, 1990) and even though these data were generated several years ago, evidence shows that stigma attributed to obesity has gained intensity (Latner & Stunkard, 2003).

Stigmatization in Healthcare: Perspectives of Obese Persons

Many of the studies reporting on the perspectives of obese persons regarding stigmatization in healthcare settings were conducted several years ago (Wadden et al., 2000; Hebl & Xu, 2001; Hoppe & Ogden, 1997; Culbertson & Smolen, 1999; Maroney

& Golub, 1992); however, recent studies (Berryman et al.; 2006; Jeffrey & Kitto, 2006) report similar findings. The three studies addressed in this section found that experiences of obesity stigma-related situations were reported as common occurrences among all participants. Women reported encounters of stigmatization by their HCPs, expressed frustration with the HCPs, perceived that the negative treatment they received was directly related to their weights and were ambivalent about the services they received (Brown, Thompson, Tod, & Jones, 2006; Cossrow, Jeffrey, & McGuire, 2001; Puhl et al., 2007).

A participant in one study reported that even when she visited the physician for another complaint totally different from her weight, the complaint was ignored and the focus became her weight (Cossrow et al., 2001). Additionally, women reported greater variety and numbers of negative experiences because of their weights than did men in the study (Cossrow et al., 2001). The internalization of obesity stigma by persons who are obese was evidenced in the reports of participants who voiced that they expected encounters of negative stereotypes in social interactions, including the healthcare environment (Brown et al., 2006). This comment by participants alludes to the pervasiveness of obesity stigmatization in society and the fact that it may be so powerful that some persons who are obese may perceive it as the norm. Participants in one study suggested several interventions to address the issue of obesity stigma, including educating HCPs on the fact that excess weight should not be the first or only thing to be considered when meeting an obese person (Puhl et al., 2007). If this perceived behavior

on the part of HCPs is widespread, then it is not difficult to imagine the influence it may have on utilization of healthcare services by obese women.

Even though these studies provide excellent data on the issue, as discussed earlier, they do not represent the viewpoint of AAW. In almost all of the studies, AAW were either not represented, under-represented or the researcher failed to explicitly state the inclusion of this group in the study.

Stigmatization in Healthcare: Perspectives of Health Care Providers

The perspectives of HCPs regarding obese persons are just as valuable as the perspectives of the obese individuals themselves because the HCPs perspectives can validate the reports of stigmatization given by obese persons. It has been reported that the same stigmatizing views about obesity that are pervasive in the general public, exist among health care practitioners and this negative viewpoint impacts the care delivery to obese persons (Fabricatore, Wadden, & Foster, 2005). The discussion in this section will elaborate on obesity stigma as it is researched in the general population of health care practitioners but will also highlight the issue as it is addressed in specific groups of health care practitioners. Several studies have reported biases held by HCPs in the perceptions and treatment of obese persons (Brown, Stride, Psarou, Brewins, & Thompson, 2007; Foster et al., 2003; Greenwald, McGhee, & Schwartz, 1998; Harvey, Summerbell, Kirk, & Hills, 2002; Hebl & Xu, 2001; Jay et al., 2009; Maroney & Golub, 1992; Petrich, 2000; Poon & Tarrant, 2009).

In several quantitative studies, the Implicit Association Test (IAT) was used to examine obesity stigmatization among HCPs and findings showed that HCPs endorsed

the implicit and explicit stereotypes that obese persons are lazy, bad, stupid and worthless (Greenwald et al., 1998; Schawrtz, Chambliss, Brownell, Blair, & Billington, 2003; Teachman & Browell, 2001; Vallis et al., 2007). In Vallis, et al. (2007), the participants (n=78) were all HCP, with women comprising 89% of the sample. Physicians, nurses and dietitians made up most of the sample with 14%, 15% and 37 % respectively. In contrast over 30% of the sample in Schwartz et al. (2003) was comprised of physicians; nurses and dietitians made up very small percentage of the sample, about 2% and 8% respectively. Evidence also exists that obese persons are perceived as physically unattractive, undesirable and having responsibility for their weight problems (Carr & Friedman, 2006). In addition, some physicians demonstrated less investment in patients who did not lose weight as they were instructed; these actions may cause the obese patient to become discouraged (Howe, 2006) and quite likely delay or avoid healthcare.

Even though recent studies examining perceptions of nurses regarding obesity are sparse, researchers have examined this issue among nurses in past years and have found similarities to perceptions of physicians. Findings in three qualitative studies were consistent and showed that nurses did not view larger body sizes in a positive light, felt repulsed when providing care to obese patients, were uneasy about discussing weight with their patients, believed that obese persons lacked self-will and perceived that most problems obese persons had were attributed to their weight (Bagley et al., 1989; Garner & Nichol, 1998; Maroney & Golub, 1992). Sample sizes in these studies varied (n=10 to n=398).

In contrast to these findings, findings from two studies in recent years showed that few nurses expressed negative attitudes toward obese persons (Brown & Thompson., 2007; Zuzelo & Seminara, 2006). Specifically, over 60% of nurses disagreed that obese persons are lazier than non-obese individuals and only 4% reported feelings of disgust while caring for these patients (Brown & Thompson 2007). In addition, even though some nurses expressed feeling dread and fear while caring for obese patients and worried about their physical safety, very few expressed having negative attitudes toward these patients (Zuzelo & Seminara, 2006).

Explanations for the inconsistencies in the old and new studies have not been offered by the researchers. My assumption is that the latter two studies were conducted more recently and with the increased attention placed on obesity in recent years, HCPs may have become tolerant and sensitive to the issue. However, since these are only two of a few recent studies on the issue, this assumption cannot be validated without additional studies.

The beliefs of registered dietitians, another group of healthcare professionals who closely interact with obese persons, have also been studied. As with nurses, there is a paucity of recent studies addressing the phenomenon in this population of HCPs. Nevertheless, the studies conducted have had similar findings. Compared with overweight persons, dietitians have rated obese persons as less healthy, less likely to be successful workers, having a greater likelihood that people would be uncomfortable associating with them, and as being more likely to experience shame because of their weights (Harvey et al., 2002; McArthur & Ross, 1997; Oberrieder, Walker, Monroe, &

Adeyanju, 1995). The viewpoint that obese persons are not able to establish weight loss goals that are realistic have also been expressed by some physicians while others have attributed emotional problems to the cause of these individuals' excess weight (McArthur & Ross, 1997).

The stigma associated with obesity is not just pervasive in practicing HCPs; students in healthcare fields have exhibited similar biases toward obese individuals. While there are few recent studies examining this issue in healthcare students, the studies attest to the fact that obesity stigmatization exists in this population of future HCPs. Three descriptive (Blumberg & Mellis, 1995; Culbertson & Smolen, 1999; Petrich, 2000) and two intervention (Puhl, Schwartz, & Brownell, 2005; Wiese, Wilson, Jones, & Neises, 1992) studies addressing the issue will be discussed in this section. Descriptive studies will be discussed first.

In two studies, nursing students reported that they were uncomfortable when they had to provide care to obese patients and would not care for these patients if they had a choice (Culbertson & Smolen, 1999; Petrich, 2000). A large percentage of the students (58%) felt that caring for obese persons was physically draining (Culbertson & Smolen, 1999). Similar to practicing nurses (discussed earlier), some nursing students expressed repulsion at the sight of obese persons and believed that all obese persons were unhealthy (Petrich, 2000). In the third descriptive study, 100 medical students were surveyed and 59% of the students gave several derogatory responses when asked about their initial reaction to a person weighing 350 pounds. Scorn and disgust were their most frequent responses (Blumberg & Mellis, 1995).

Caring for obese persons has obvious challenges (i.e., heavier to lift, more difficult to perform certain procedures, etc.) and it is understandable that care for the obese patient may be physically exhausting. However, obese patients should not be subjected to display of negative attitudes while utilizing healthcare services but should receive the same un-biased care that is afforded to non-obese persons. As alluded to earlier, such overt stigmatization by HCPs may no longer exist with the advent of increased awareness regarding obesity in recent years; however, because the evidence suggests that stigmatization in healthcare settings still exists, it may be assumed that the negative attitudes associated with obesity stigmatization that obese persons encounter in healthcare settings may be more covert and subtle.

In the first intervention study, Wiese et al. (1992) developed and evaluated an educational intervention designed to change the stigma of obesity held by first year medical students. Prior to the educational intervention, the medical students held negative stereotypical attitudes regarding obese persons, perceiving them to be ugly and lacking in self-will. One year post-intervention, the medical students were more likely to attribute obesity to genetic factors instead of blaming obese persons for the condition.

Puhl et al (2005) conducted a more recent intervention study aimed at decreasing obesity stigmatization. They used the Perceived Social Consensus Model as an intervention to reduce obesity bias in a group of college students enrolled in psychology classes. The perceived social consensus model proposes that stigma and stereotypes are both functions of how a person perceives that others in his/her social group views obesity. Participants in the study reduced their negative perceptions of obese persons

when they learned that others in their social in-group held more favorable views of obese persons.

The two intervention studies are testament to the fact that even though the stigma of obesity may be rife among healthcare practitioners, the widely held negative beliefs may be modifiable with the appropriate interventions. The beliefs of others who are in one's social group and educational interventions are just two methods that may be beneficial in changing negative attitudes toward obesity. Therefore, if HCPs who have negative attitudes toward obese persons perceive that others who are their peers do not harbor negative attitudes toward obese persons, they may significantly decrease their own negative perceptions.

The findings in these studies consistently demonstrate that negative attitudes and beliefs about obese persons are evident among HCPs who care for this population. It should be considered that such stigmatization may impact the decisions of AAW to utilize preventative healthcare services. Healthcare providers are "front–line" practitioners who interact with obese persons on a daily basis and are very influential in the healthcare of these individuals. How their interactions with obese women seeking healthcare are perceived by the women themselves can significantly influence the healthcare utilization behaviors of these women.

Stigmatization and Healthcare Utilization

Despite the fact that the literature suggests the existence of obesity stigmatization in healthcare settings, there are limited studies that examine the influence of obesity stigma on healthcare utilization by obese persons. However, studies demonstrate that

obese women are reluctant to utilize healthcare, primarily for services that are preventative in nature (Fontaine et al., 1998; Howe, 2006; Meisinger, Heier, & Loewel, 2004; Olson, et al., 1994; Wee et al., 2000). In addition, they frequently change providers (Howe, 2006). Brownell et al. (2005) posit that such behaviors can be as a result of patients' embarrassment because of their increased weights or their perceived disapproval from physicians which cause them to seek out other healthcare providers who are sympathetic toward them. Some women have identified lack of respect and inadequate and undersized equipment as factors impacting use of timely healthcare services (Amy et al., 2006; Fontaine et al., 1998).

Merrill & Grassley (2008) conducted a qualitative study of overweight and obese women (n=8) about their life experiences as overweight individuals. The women reported major challenges to fit into the sphere of healthcare services. They experienced heightened awareness and dread in waiting rooms and examination rooms because of inadequate spaces, equipment and examination gowns. In addition, participants reported that HCPs dismissed them, did not believe their complaints or refused to focus on their complaints, focusing instead on their weight. Further reports from participants were that HCPs did not take time to hear them and so they felt that they were not listened to. The women feared seeking healthcare when the relationships with HCPs were not good; sometimes, encounters with HCPs were perceived as embarrassing and debasing. In addition, participants described their encounters in seeking healthcare as a "constant struggle." The reports of these women attest to the existence of obesity stigma in healthcare settings and the impact it has on obese women. Some obese persons have

reported that when good relationships and positive interactions with their HCPs are fostered, the negative effects of obesity stigmatization are partially amended (Brown et al., 2006).

In a more recent study, Fair et al. (2009) examined the relationship between obesity and adherence to screening mammography (n=76). About 64 % of those classified as obese, compared to 35.3% of non-obese women, delayed their return for resolution of an abnormal mammogram. Further, it is suggested that obese women are not receiving optimal care when it comes to preventative services, partly due to negative attitudes of HCP (Howe, 2006). The evidence demonstrates the pervasiveness of negative attitudes toward obese persons and highlights the reason why obese women may not willingly use healthcare. As Brownell et al. (2005) posit, the introduction of obesity bias in the healthcare setting causes patients to have negative responses which may trigger an effect of greater risk of healthcare avoidance by these patients, resulting in increased complications of obesity.

It is important to note that the negative attitudes that obese AAW experience with HCP may be attributed, to some degree, to their gender and race. It appears that just being "female" predisposes a woman to differences in treatment in the healthcare setting. It is reported that women receive inferior healthcare from HCP compared to their male counterparts and experience worse health outcomes (U.S. Department of Health and Human Services: Office of Women's Health [DHHS-OWH], 2007). For example women receive less health counseling (Agency for Healthcare Quality and Research [AHRQ], 2004), fewer screens for colon cancer (Woods, Basho, & Engel, 2006), worse diabetes

care (Correa-de-Araujo, McDermott, & Moy, 2006) and significantly worse cardiology care (Daly et al., 2006). In addition, it has been reported that even when men and women have the same rates of a disease, the referral for the condition is different, with men being referred more frequently (DHHS-OWH, 2007). Compounding the problem in AAW is the issue of race.

African Americans (AA) receive consistently poorer care from HCPs even when insurance is not a factor (Smedley, Stith, & Nelson, 2003), are less likely to receive needed cardiac procedures, and have higher mortality rates from heart disease (AHRQ, 2004). In addition, African Americans (AA) receive significantly worse health care for diabetes than Caucasian Americans (Virnig et al., 2002). It is suggested that because of the vulnerability to prejudice that exist with AA, a major reason for the worsened healthcare in this population may be behaviors of HCPs (Thorburn & Bogart, 2005). With the multiplicity of problems that AAW face because of gender and race, it is not difficult to envision that when obesity is added to these issues, stigmatization of AAW may be magnified. However, one major difference between biases based on gender and race and obesity is the fact that the former two biases are protected by public policies (i.e. women's rights, policies preventing blatant racism, etc.) but the latter has no public policy that prevents its stigmatization.

Assumptions

The Interaction Model of Client Health Behavior (IMCHB) (Figure 1) will frame my assumptions for this study. The IMCHB was developed by Cox (1982, 2003). The client-professional interaction is a major aspect of this model. The role of the HCP in

having a positive or negative impact on the client's health outcomes and healthcare decisions are prominent in the framework (Cox, 1982). The model proposes that the HCP's interaction style and approach toward clients have the ability to support or discourage the client's health behaviors. African American women who perceive negative interactions with HCPS may make the decision to delay or avoid utilization of healthcare for preventative services, a decision that can have harmful health outcomes. There are four assumptions underlying this study:

1. Obese AAW will honestly recount their experiences living as obese individuals.
2. In their interactions with healthcare providers, obese AAW encounter stigmatization because of their weights and their stories will reflect poor utilization of preventative healthcare services because of these interactions.
3. AAW with BMIs greater than 40 will recount more vivid experiences of obesity stigmatization in healthcare settings.
4. The use of a phenomenological design will allow the stories of the women to be heard and explicitly told by the researcher; the stories will help to inform development of interventions that may prevent obesity stigmatization, increase healthcare utilization and prevent poor health outcomes.

Figure 1: Interaction Model of Client Health Behavior

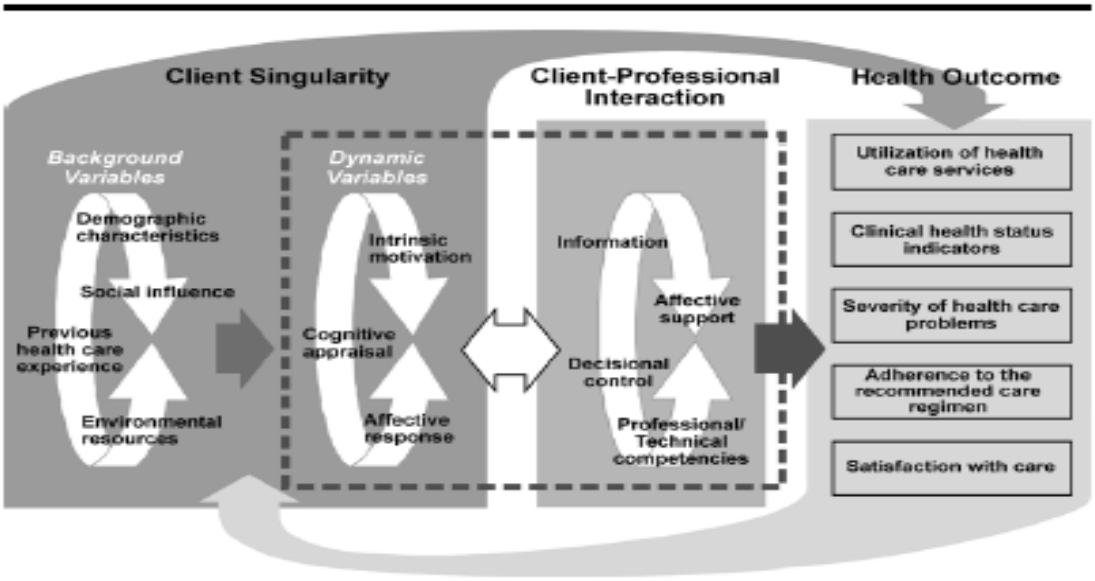

Figure 1. Interaction Model of Client Health Behavior

Summary

This review of literature is important to the study; it supports my assumption that obese women encounter stigmatization in healthcare settings and are treated negatively by some healthcare providers. These data also validate the reluctance that is seen in obese women to readily utilize healthcare services for health care screens that can significantly impact the breast and gynecological cancers that affect obese women disproportionately. Because of the high prevalence of obesity in AAW, the high risk for breast and gynecological cancers and the fact that AAW die disproportionately from breast cancers, it is of paramount importance that these women seek, and are afforded, timely and sensitive healthcare access.

Even though the literature supports the assumption that women delay utilizing healthcare because of stigmatization, there remains a significantly large gap in the understanding of this phenomenon. This gap lies in the fact that existing studies on the issue include samples that have been skewed toward White American women while others have not elaborated on the ethnic composite of the samples. The findings in the studies are therefore not representative of AAW, the group most affected by obesity. In addition, many studies addressing the issue are outdated and not representative of a phenomenon that has worsened drastically in the past 20 years. Furthermore, researchers studying utilization of healthcare services by obese persons have not agreed on a definitive measure of healthcare utilization but have used varied approaches and definitions. Moreover, the studies have focused primarily on quantitative measures; qualitative studies on the phenomenon have been lacking. Examining healthcare utilization qualitatively may allow obese women to voice experiences regarding their utilization of healthcare services that could not otherwise have been captured quantitatively. Their stories may give us insight into why they chose to use or not use these services. Ultimately, examining the issue of preventative healthcare utilization from the perspectives of obese women may have significant implications for HCPs and policy makers.

With the known risk of breast and gynecological cancers that obese women have and the high mortality from breast cancer that is present in obese AAW, HCPs need to be aware of the healthcare utilization or avoidance behaviors of this population and be ready to use the data to provide needed education to these women. In addition, HCP's are the

nucleus of the healthcare system and are relied upon by obese clients for information and education regarding health needs. Results of this study may also provide rich data that can be used to (1) employ health policies aimed at addressing negative reasons that prevent AAW from utilizing preventative healthcare services, (2) foster early and timely screens for breast and gynecological cancers in AAW, and (3) decrease deaths from these cancers in AAW. This study proposes to hear the stories of obese AAW.

CHAPTER III

Methodology

Design

The aim of this study was to explore the experiences of obese African American women (AAW) as they have used healthcare services and to understand if the encounters with healthcare providers have impacted utilization of preventative healthcare services (mammography & Papanicolau screens) by this group of women. This chapter delineates the methodology that was used to conduct the study and includes the following sections: design, sample, recruitment, data collection, data analysis, trustworthiness of the study and protection of human subjects.

Interpretive hermeneutic phenomenology, based on the work of Max van Manen (1997), was chosen to guide the process in this study. This methodology is focused on the individual's life world or human experience as it is lived (van Manen, 1997) and is therefore particularly beneficial as a guide for this study. Hermeneutic phenomenology allows for the attainment of a rich description of experiences of obese African American women told in their voices. In addition, it allows the researcher to understand the essence of the women's lived experiences (van Manen, 1997). The interpretive approach further aids in the understanding of participant's experiences (Ajjawi & Higgs, 2007). The hermeneutic approach to phenomenology requires that the researcher employs a method of self-reflection (Laverty, 2003). Instead of setting aside his or her biases and

assumptions, the researcher entrenches them in the study, allowing them to become essential aspects of the study's interpretative process (Laverty, 2003). As the study progresses, the researcher is required to give much thought to his or her own experiences and recognize the means by which those experiences are linked to the topic being studied (Laverty, 2003).

van Manen's phenomenology has a strong focus on the researcher re-reading the stories of the participants repeatedly in order to have a firm understanding of themes that are revealed (Lane, 2005). The life-world of the individual as it is experienced and not as it is seen conceptually is the key focus of phenomenology (Munhall, 2007, p. 163). One key aspect of this methodology is learning to hear what is not said by the participant. Hence, silence is important. van Manen (1997) reinforced the importance of the researcher paying attention to silence and hearing what is unspoken by the participant, reading between the lines. According to van Manen, this is when the researcher may hear something that is taken for granted. Hermeneutic phenomenology aims to select participants to a study who have lived the experience and who demonstrate willingness to talk about these experiences. In addition, participants should have diversity so that the richness and uniqueness of stories told can be enhanced (van Manen, 1997). To that end, hermeneutic phenomenology was used in this study to explore the lived experiences of obese AAW as they utilized healthcare services and the overarching research question was, "What experiences do obese AAW have as they utilize healthcare services?"

Sample

A purposive sampling was used in the study. This method was used to ensure the selection of only participants who have lived the stories of obesity and may therefore be better equipped to recount their stories. To be included in the study, participants met the following inclusion criteria: (a) identified herself as an African American woman (men were not included because even though many men are obese, they do not have the highest obesity rate nor do they have the major issues of breast and gynecological cancers that are seen in obese women); (b) spoke, understood and wrote the English language; (c) had a BMI of 35 or higher (e.g., weight of 180 pounds and height of 60 inches. BMIs were calculated with self reported heights and weights), and (d) age 18 years or older. Participants under age 18 are still considered children. Even though children are obese, they are not included in this study because developmentally, they are different than adults and they do not make independent decisions about healthcare utilization; those decisions are made for them by adults. They may not be able to accurately recollect experiences they have had as they utilize healthcare services. Therefore, their opinions may be the perceptions of their adult caregivers instead of their own viewpoints. For those reasons, inclusion of children in the study would not be beneficial to the issue being studied. Excluded from the study were participants under age 18 and those with reported or observed cognitive impairment, such as dementia.

Recruitment of Participants

Prior to recruitment, the researcher obtained IRB approval from Georgia State University. Participants were recruited into the study via flyers that were placed in

several public areas in the metro Atlanta area: (1) the waiting room s of two emergency departments at hospitals in the metro Atlanta area; (2) the waiting rooms of various health clinics in predominantly African American communities in metro Atlanta; (3) the bulletin boards of several African American churches in the metro Atlanta area; and, (4) other venues in the community (i.e. grocery stores, pharmacies etc). Additional recruitment methods were referrals from participants who agreed to be in the study and referrals from friends and colleagues of the researcher.

The recruitment flyer was written at an eighth grade reading level and included the following: (a) a clear and concise purpose of the research study; (b) the inclusion and exclusion criteria that were used to establish participation into the study; (c) the benefits to the participant for being in the study; (d) the time and commitment required of the participant; (e) a brief summary of the study's procedure; (f) the compensation that the participant would receive for involvement in the study; and, (g) the location and contact information for the researcher. Potential participants were instructed to contact the researcher via the telephone number listed on the flyer.

Participants who expressed interest in the study were screened via telephone at the time of their initial contact with the researcher to determine if they met inclusion criteria. To establish the weight criterion, they were asked to verbalize their heights and weights and the researcher calculated a BMI while on the telephone with the participant using the formula: Weight in pounds divided by height in inches squared and multiply by 703. (Wt (lbs) / ht (inches)^2 x 703) (Centers for Disease Control and Prevention, 2011). At that time, the study was explained and their willingness to participate was ascertained.

An in-person meeting was then scheduled with the participant at a time and location that was safe, quiet and mutually acceptable to both PI and participant and that was conducive to privacy and confidentiality. Participants were informed that a consent form would be mailed to them within one week; they were advised to carefully review the form before they had the in-person meeting with the researcher. They were also told that they could call the researcher at any time prior to the interview should they have any questions.

Data Collection

At the in-person meeting and prior to data collection, the study was again explained in-depth to the participant; questions were answered and the participant signed the informed consent. A copy of the consent, also signed by the researcher, was given to the participant. An in-person one-on-one interview, instead of a telephone interview, was chosen as the primary approach of data collection. This is because an in-person interview allows any researcher the opportunity to visualize the participant's body language and use of non-verbal communication (i.e. nod, smile, frown, silence, etc.). These non-verbal forms of communication may provide insight into or clarification of the participant's verbal communication. A telephone interview cannot offer this. Thirty to 75 minute audio-taped interviews were conducted in the mutually agreed upon safe, quiet and private location (i.e., researcher's office, participant's home, library, etc.). An interview setting that is private allows for minimal distractions. It is, therefore, conducive to the participants' sharing of their stories in an uninterrupted manner as well as the researcher's immersion in the participants' stories without encumbrances. Moreover, privacy, as well as the individual interview approach gives the participant, who may be

self-conscious or bashful, a forum to share her story without embarrassment or fear. In addition, interviews can allow for a greater degree of interaction between the researcher and each participant, clarification of participant stories, and better interpretation and understanding of told stories. The participants also completed a demographic data collection tool developed by the researcher.

Questions asked were simple, clear and open-ended. The interview started with a general broad question, "Tell me your experiences as an overweight African American woman?" and proceeded to more specific and purposeful questions. These included questions such as "Tell me about a time that stands out in your mind about being an overweight African American woman needing healthcare?" If the participant talked in general terms or did not address several areas of healthcare and various healthcare providers in her stories, she was asked about specific healthcare areas and providers. For instance, one question was, "Tell me about a time that you can recall about being an overweight African American woman needing healthcare from a nurse practitioner ….medical doctor…psychologist, nurse, etc."? Also, if the participant did not readily share experiences regarding women's health visits, probing questions were asked aimed at her story as an overweight woman seeking care for women's health issues (gynecological care and mammograms). As the interview progressed, other probing questions and statements were used such as "You mentioned…..tell me more about that." What else occurred?" or "You talked about……please describe that experience in as much detail as possible." "You said…..would you explain why you believe that?" Those questions were designed to be congruent with the hermeneutic phenomenological

perspective because they were not closed ended, requiring brief responses. Instead, they were open-ended and promoted greater storytelling and re-living of the experience by participants. In addition, open-ended questions that elicit rich descriptions from participants who have lived the experience of obesity stigmatization ensure that the researcher rewrites the story exactly as told; this increases the credibility of the results of the study. Fifteen participants were interviewed; data were collected until saturation was reached. Follow-up interviews were conducted with a sub-set of this sample. For their participation in the study, each participant received a $20.00 gift card.

Data Analysis

Qualitative data analysis in the van Manen hermeneutic phenomenology approach requires that the researcher reads the field data multiple times in order to accurately re-tell the participants' stories (van Manen, 1997). Therefore, data analysis included full immersion in the data so that the researcher could engage in initial data interpretation that guided later data coding. Qualitative data analysis and collection occurred concurrently fostering interpretation of stories already told by the participants and creating an avenue for additional questions. All interviews were transcribed verbatim and transcripts were loaded into a computer program used for retrieving and organizing qualitative data. Keeping true to the hermeneutic phenomenology approach, data were analyzed in its entirety then in segments (one line at a time). This aided in the recognition of overarching themes in the participants' stories. The data were coded and labels were given to identify particular themes in the data. For example, if the participants described negative encounters with providers, this was coded as "negative treatment." This coding continued

until all data were appropriately coded. All similar codes were grouped and from these groupings, the researcher identified similar themes.

Authenticity and Trustworthiness

When conducting any research study, every effort must be taken to ensure that the study is rigorously conducted and that much attention is given to accuracy and precision of every area of the study. Conducting a study in this manner will determine the believability and transferability of the findings. In qualitative studies, rigor is determined by the study's dependability, confirmability, credibility and transferability (Lincoln & Guba, 1985). Dependability addresses the ability of another researcher to arrive at the same or similar conclusions in a study based on the data acquired by and the perspectives of the researcher who conducted the study. To achieve dependability in this study, the researcher kept all audiotapes, notes, journals, codes, etc, in the event that an audit needs to be conducted.

Confirmability refers to the ability of the researcher to maintain a neutral stance in the study by not introducing any personal biases into the study. Confirmability further speaks to the extent to which the results of a qualitative study can be confirmed. This study ensured confirmability by cultivating a research process where excellent keeping of all records pertinent to the study was enforced. The researcher will keep all research journals, audio taped interviews, field notes, transcripts and any research reports for a period of five years following the completion of the study. In addition, the researcher clearly declared her personal perspective by identifying assumptions regarding the phenomenon being studied and findings that were anticipated.

Credibility is the researcher's ability to correctly depict the participants' lived experiences as they are told by the participants in a manner that the participants could recognize. Credibility in this study was achieved in several ways. First, a prolonged engagement with the participants by staying as long as possible with them ensured that their voices were heard; this means that the researcher was available to the participant from the initial contact to the end of the study. The researcher took the time before the start of the interview session to converse casually with the participant in order to develop rapport. Follow-up interviews were also conducted.

Second, immersion in the study is necessary to be able to distinguish between data that are relevant and those that are irrelevant; that is, from the start to the completion of the study, the researcher continuously read, re-read and analyzed data without allowing a lapse in time when the data was not being analyzed. By doing this, the researcher became very familiar with the participants and the data, and was able to identify subtle details that were relevant to the study as opposed to information that was worthless. Other strategies for maintaining credibility included (a) using multiple data collection methods (i.e., interviews, field notes); (b) performing member checks by having participants in the study read transcripts in order to determine accuracy of the data and to gain the insight of the participants; (c) having dissertation committee members and other peers review data collection and analysis of the study to gain fresh perspective on the study and capture any participant story that may have been missed; and (d) giving particular attention to aspects of the participants' conversations that were of particular significance to the phenomenon being studied.

Transferability in a qualitative study refers to the transfer of the study's conclusions to other settings. This study promoted transferability by the selection of a purposive sample of participants, research setting, and recruitment methods that were clearly delineated. This allows for easy transfer of findings to other samples. The fact that the study proposed to report vivid narratives of the participants' stories gives others interested in using the findings from this study the information necessary to determine the appropriateness of transferring the findings to other groups. In addition, providing all the pertinent findings from the study allows others to decide if the results are applicable to their population.

Protection of Human Subjects

Ethical Considerations

Ethical and legal rights of all human subjects were maintained throughout the study. Institutional review board approval was obtained from Georgia State University. Participants in the study did so voluntarily and were be coerced. The risks to participants were no more than would be in normal everyday life. However, participants might have recollected experiences with healthcare providers that were distressing to them and caused them to become upset. In the event that they became overwhelmed while sharing their experiences, they were allowed to stop the interview and resume at a time that was acceptable to them. Two participants became visibly upset while sharing their stories; however, they recollected themselves fairly quickly, did not wish to stop the interview and continued without further distress. If they wished to discontinue participation in the

study, they could withdraw without penalty or repercussions. No participant withdrew from the study.

Direct benefits to participants were not expected but benefits to society may be many. Findings that obese African American women are delaying use of preventative healthcare services because of biases on the parts of healthcare providers, could be used to increase education to healthcare providers caring for obese persons. This education may allow for more sensitive care, which may give obese individuals a sense that they can be cared for without the stigma associated with obesity. As a result, obese women may seek preventative healthcare services more readily. The overall benefit to society from the women's readiness to seek preventative healthcare is lowered rates of associated cancers and lowered financial burden. Privacy and confidentiality of participants' data were ensured. Data is kept in a locked and secured cabinet, to which only the researcher has access; data will be shredded after five years. Published results of the study will not have any participant identifying information.

Minorities

The study examined a sample of African American women only. The fact that obesity in the United States is disproportionately high in African American women justified the need to study this defined population and not any of the other minority populations. As explained earlier, this study did not include children for reasons already addressed in inclusion/exclusion criteria.

Summary

In summary, this chapter outlined the study's methodology. The design, sample, recruitment, data collection and data analysis have been clearly delineated and aspects of human subject protection have been addressed. The chapter has also defined the means by which the researcher ensured trustworthiness of the study by examining the issues of credibility, confirmability, dependability and transferability. This methodology was the most appropriate for this qualitative study and the sensitive topic of obesity.

CHAPTER IV

Research Process

This chapter outlines how the research plan was carried out in this study. It describes the recruitment of participants, generation of data, settings in which data were collected, and delineates an audit trail concerning the process of the research inquiry.

Recruitment

Participants were recruited using purposive sampling to ensure that only individuals who met the inclusion criteria, lived the experience of obesity and were therefore well equipped to tell their stories, would be included in the study. Flyers were posted in various locations: clinics, hospital emergency rooms, churches, beauty shops, pharmacies, grocery stores and community bulletin boards. Referrals to the study also came from participants who agreed to be in the study. Another key source of recruitment was referrals from friends and colleagues of the researcher; even though the majority of the sample came from this latter method of recruitment, the other methods were also contributory to the recruitment process.

To determine the body mass index (BMI) inclusion criterion, individuals who expressed willingness to participate in the study-self reported their heights and most recent weights and the researcher used these data to calculate their BMIs. Additional inclusion criteria were ascertained, also via self-reports from the participants (i.e., age,

and ethnicity). One participant did not meet inclusion criteria, based on body mass index and was therefore not allowed in the study.

The original research plan stated that consent forms would be mailed to participants within one week after they expressed willingness to be in the study, prior to setting up the initial interview meetings with them. However, this did not always occur. This deviation in the research plan occurred because the majority of the sample scheduled initial interviews within one week of their agreement to be in the study; many were interviewed within 2-3 days of their agreement. In view of this fact, mailing the consent forms to those participants would have been pointless as they would not have received the consent forms prior to time of the interview meeting. They were given adequate time to read the forms, ask questions and ask for clarification on any aspect of the form that they did not clearly understand.

Data Generation: Initial Interviews

IRB approval was received for the study. Prior to the start of each interview, the study was again explained to participants. Their questions were answered and consents were signed. Signed copies of the consent form were mailed to participants within seven days; three participants had copiers in their homes so they received copies of their signed consents at the time of their interviews. Along with inclusion criteria (aforementioned), demographic data were collected for each participant prior to the start of each interview. Demographic data included marital status, employment status, and health insurance status as well as level of education. Since age was an inclusion criterion, participants' ages

were ascertained at the initial communication with the participant, prior to data collection, and not at the time of demographic data collection.

A total of fifteen in-person, individual, audio-taped initial interviews were conducted by the PI in various settings. Due to the potential for unsafe situations, the researcher's preference was to conduct all interviews in public locations and not in participants' homes. However, at the request of several participants, six interviews were conducted in participants' homes because it was more convenient for these participants.

The researcher was always aware of the environment in settings where interviews were conducted in participants' homes, carefully researching, as best as possible, the communities where the homes were located prior to the schedule interview. Research included asking others about their knowledge of the community and using the internet to identify any significantly negative aspects of the community that would present potential substantial risk to the researcher. Moreover, scrutiny of the community where homes were located was done prior to each interview. This was accomplished by the researcher arriving in the immediate community early and taking the time to identify sights and sounds of the community. In addition, upon entering the homes, measures to ensure a reasonable degree of safety were strictly adhered to. These measures included a quick scan of the home interior immediately upon entering, looking for any apparent unsafe situations. None of the home interview settings was deemed unsafe. One interview that was to be held in a quiet, private room in a library had to be moved to the participant's home nearby as the pre-set library setting was occupied. Because the participant's home was located in a community fairly close to the researcher's residence, the researcher was

familiar with the participant's community and was therefore not apprehensive about safety issues. Even though this participant expressed the fear that her two small children might interrupt the interview process, their interruption was minimal as the participant's spouse kept them away from the immediate interview setting.

One interview was conducted in the researcher's office and was scheduled for a time of day when the setting would be quiet with minimal to no distractions. Another interview, scheduled to be conducted in a fast food restaurant had to be changed to an alternate fast food restaurant. Even though the interview was scheduled at a time of the day and day of the week when the restaurant had minimal customers and was therefore conducive to privacy and confidentiality, there was unanticipated music playing loudly overhead that would have rendered the interview futile. The new location proved to be ideal as traffic in and out of the restaurant was almost non-existent at that time of the morning; the setting was very quiet and private.

The remaining six interviews were conducted in public library settings. They were done at a time of day when the libraries were sparsely populated and settings favorable to audio-taping. All interview settings were mutually acceptable to participants and the researcher and conducive to privacy and confidentiality.

Initial audio-taped interviews lasted for 30-60 minutes, with a few lasting over 60 minutes. Consistent with the research plan, interview questions were simple, clear and open ended. The interview started with very broad and general questions, such as, "I am really interested in hearing the stories of overweight African American women and the experiences they have had in healthcare settings but first, if you were to say, this is the

experience of a full-figured or overweight African American woman living in America, what general story would you tell?" Questions proceeded in a more focused and specific manner, for example, "Would you tell me your story as an overweight or full-figured African American woman using healthcare services?" "Tell me about a time that stands out in your mind about being an overweight African American woman needing healthcare?" or "What experiences have you had with health care providers in any healthcare setting?" Other probing questions were asked when necessary, aimed at answering research questions that were not answered with stories elicited from broad or specific questions. The participants remained calm and relaxed during the interviews. Many augmented their verbal stories with various hand gestures and facial expressions, which made their stories more vivid and sometimes, dramatic.

Data Generation: Follow-up Interviews

Obtaining follow-up interviews deviated somewhat from the research plan in that not all follow-up interviews were obtained within one month of the initial interview. This deviation occurred because obtaining follow-up interviews proved to be a challenging, and sometimes daunting process that was prolonged because of the inability to verbally communicate with participants when timely attempts were made by the researcher. Even though half of the sample willingly provided follow-up interviews, once the researcher was eventually able to speak with them, actually contacting them was the challenge. Repeated telephone calls were made to many participants but calls were not answered. Voice mail messages were left by the researcher at the first and second calls but no messages were returned.

Not wanting to infuriate or repel participants by appearing pesky, the researcher was very careful in the choice of words left on each participant's voice mail. With each message left, the researcher added an expression of gratitude to the participant for the initial interview and reminded her of the invaluable nature of the story she told. After a third call, some participants returned calls to the researcher while a few actually answered their telephones. No participant was called more than four times.

A total of seven audio-taped, in-person individual follow-up interviews were conducted in various settings. The researcher started all follow-up interviews by asking participants if they had any questions, concerns, or if they thought of anything since the first interview that they would like to now share. Except for one participant who was concerned that she may have talked too much about her failed marriage and not given me the information I really needed when I first interviewed her, no participant relayed any concerns or had any questions at or after the follow-up interviews. Two interviews occurred in participants' homes and the safety measures followed in the initial interviews were also adhered to in these follow-up interviews. Two interviews were scheduled to be conducted in libraries; however, due to unforeseen interruptions in these locations that would have impeded privacy, one that was to be in the library on the researcher's college campus was changed to the researcher's office; the other was moved to a quiet bench outside that library. Of the remaining three interviews, two were conducted in fast food restaurants and the other in the participant's car.

The setting for this last interview was such because the participant requested the interview on her lunch break at work. Since the researcher had tried exhaustively to

solidify a follow-up interview with this participant, the participant's willingness to be interviewed, even if on her lunch break, was a welcome opportunity. The participant had scheduled her lunch break for later than normal, at a time when she anticipated that the cafeteria would be sparsely populated; however, the atmosphere in the cafeteria did not afford privacy and confidentiality to the interview, necessitating the move to her car. Except for the last interview which lasted approximately 20 minutes, all follow-up interviews lasted 30-60 minutes. As with the initial interviews, privacy and confidentiality were maintained with all follow-up interviews and interview settings being mutually agreed upon by the participants and researcher.

The research plan stipulated that follow-up interviews would to be conducted with a sub-set of the sample; therefore, interviewing a half of the sample was deemed appropriate and beneficial to the study. Additionally, the follow-up interviews allowed the researcher to clarify data gathered in the first interview that may have seemed ambiguous. Furthermore, follow-up interviews provided the opportunity for participants to engage in member checks of their interview transcripts, which enhanced the trustworthiness of the study.

Data Analysis

All audio-taped initial and follow-up interviews were transcribed verbatim and transcripts were loaded into a qualitative analysis package (WEFT-QDA), used to organize data. Consistent with the hermeneutic phenomenology approach, transcripts were analyzed as a whole and then line-by-line, identifying patterns and themes common to transcripts. Data analyses occurred concurrently with data collection. The process

utilized an interpretive approach. This approach was beneficial because it allowed the researcher to interpret data already collected in initial interviews and created an avenue for subsequent questions in follow-up interviews. Coded data were assigned labels, identifying particular themes in the data. Similar codes were grouped and from these groupings, the researcher identified similar themes across interviews.

Trustworthiness

In the study, trustworthiness was ensured in multiple ways. First, peer review was achieved by having other researchers and peers read interview transcripts. All transcripts were read by the chair person of my dissertation committee and expert feedback was given on all transcripts reviewed. In addition, three transcripts were read by the chair of the research committee where I am employed, while four other transcripts were read by my peers, also at the university where the researcher teaches. One transcript was also read by a researcher at another institution. Other transcripts were reviewed by a fellow doctoral student. For all peer reviewed transcripts, feedback was given; feedback was valuable in that it helped me to identify areas in participants' stories that needed further explanation or clarification as well as new questions that could be generated on follow-up interviews.

Second, member checking was attained by asking participants to read transcripts of their interviews and to validate that I had accurately captured the stories they intended to tell. All participants who reviewed their transcripts agreed that their stories were accurately captured. Third, I maintained a meticulous audit trail by keeping journals and field notes throughout the study. This audit trail ensured that every minute detail related

to the study was accurately and timely chronicled. Fourth, prolonged engagement with the participants was accomplished by conversing with many participants immediately prior to the interview to build rapport, interviewing them for at least 30 minutes, with many interviews lasting 75 minutes, conducting follow-up interviews and giving each participant permission to contact me regarding any aspect of the study they may have questions or concerns about, even after the interviews have ended.

Finally, complete immersion in the study was realized by continuously reading, re-reading and analyzing data without allowing a lapse in time when the data was not being analyzed. By doing this, I became very familiar with the participants and the data, and was able to identify subtle details that were relevant to the study.

Summary

In summary, this chapter delineated how the research plan was accomplished and described my decision regarding how the inquiry process was achieved. Participants were recruited, data generated and analyses completed with only minimal deviations from the research plan; deviations were clearly explained in the chapter. The chapter also discussed the methods by which trustworthiness of the study was maintained.

CHAPTER V

Findings and Discussion

This section discusses the demographic characteristics of the sample and describes the salient patterns and themes that were identified from the analysis of data. All patterns and themes answered the research questions: RQ1:What general experiences do obese African American women have while utilizing healthcare services?, and RQ2: What negative experiences, if any, do AAW have with healthcare providers and how do these experiences factor into their decisions to utilize preventive healthcare services?

Demographic Profile

A total of 15 obese African American women were interviewed. Ages of the participants ranged from 23 to 62 years. Five (33%) of the women were married, five (33%) were single, while the remaining 34% identified themselves as either widowed or divorced. Body mass index of the women ranged from 36 to 55, with more than half the sample having BMIs of 40 or higher. Employment data showed that only 6 women (40%) were employed, while another 6 (40%) were either unemployed or full time students. Of the remaining 3 participants, 2 were retired and one identified herself as disabled and unable to work. The majority of participants (87%) had adequate health insurance while 2 (13%) women reported lack of adequate health insurance. The sample was fairly well educated; most (87%) had either completed college or had some college education.

Patterns and Themes

The participants gave vivid descriptions of their lives as obese women and how their relationships with healthcare providers were impacted by their weight status. The phenomenological analysis revealed two patterns: Pattern 1: They're Not Listening, and Pattern 2: Good or Bad, It's My Decision. Several themes emerged from these patterns. The patterns and themes materialized from the women's unique stories and elucidated the healthcare experiences of obese African American women, addressed their encounters with healthcare providers and spoke to their decisions to utilize healthcare services because of their encounters. Themes will be presented and discussed with their corresponding patterns. All patterns and themes will be substantiated by participants' quotes, which will be presented verbatim; quotes will be identified by assigned participant numbers.

Pattern #1: They're Not Listening

With this pattern three themes were identified: Theme 1: Attributing All Problems to Weight; Theme 2: They Say Lose Weight but Give Us No Tools, and Theme 3: Stigmatization. Interspersed throughout the interviews were vivid stories of the women's perceptions of not being listened to enough by healthcare providers. This pattern was pervasive among the women's stories.

Theme #1: Attributing All Problems to Weight

Many women recalled encounters where healthcare providers not only failed to listen to them but blamed their weight for every health problem they presented with. As one woman stated, "You know…they always blame the weight for everything. You walk

in there with an obvious problem and the first thing they say, it's because you are overweight. Weight may cause some problems but it is certainly not the reason for every problem." (Participant 6). She continued by saying:

> They really don't listen when you try to tell them what is going on with you… They don't listen…and then you have to go find somebody else that will listen and it is still very few out there that will listen to you. You have to really search high and low for somebody who really, truly cares about how you really feel, when you are telling them what you are feeling … It's hard to find somebody like that. (Participant 6)

Another participant said, "I left in tears because I just felt that he wasn't listening, he wasn't listening to what I was trying to say to him. I knew it was more than just weight and um…and um… I knew… and he just blew me off and ignored me." (Participant 14) Other women in the study also recalled experiences where they felt that they were not listened to. One woman stated:

> My primary doctor…and I certainly don't want to go back to her…she kind of was like…she was condescending…I didn't feel like the person took her time to listen to me. She didn't listen to me. (Participant 10)

Women in the study believed that they had valid problems that necessitated the visits to their providers. They wanted to be heard, to be taken seriously and to have resolution of the problems for which they visited the provider. The women did not mind when providers addressed their weights in a positive manner. However, they did not want their weights to be the first topic of conversation when they presented to a provider

with health problems; they wanted providers to listen to them about the symptoms they were experiencing and the reasons that necessitated the visits to the provider. Participant 12 expressed her dissatisfaction at encounters she had where providers focused on her weight instead of addressing the health condition that she went to them for. She said:

> I know that my weight may cause other issues but what I am coming to you for, if you would treat that issue first and then maybe we can get on some type of diet…you know...I want you to really look at what's wrong with me and what I'm complaining about now. I know that my weight may have caused this issue but I am having an issue right now…so help me fix this issue. I know that the weight did not come overnight and the problem that I am coming to you with, just started …so if you can help me fix this problem, then we can get to the thing that I've tried to get rid of for the last 20 years…so…um…that's it. (Participant 12)

One participant spoke of the experience she had when she went to the emergency department in an asthmatic crisis:

> I became asthmatic and had real breathing problems but when I would get there to an emergency situation, instead of them looking at me and looking at the problem, they immediately said…you know…hey…yeah, you might be asthmatic but the problem is your weight. You need to lose weight…hold it, I'm having an asthma attack right now. You don't need to address my weight…not right now. I am aware that I have that problem. (Participant 11)

This woman's story was validated by another participant who expressed her frustration because her provider failed to address her medical problem, focusing instead on her weight. The woman stated:

> If I've been in with a migraine or the flu the final analysis is…no matter what, in the exam room we're talking about, the final ending is, you need to lose weight and that's not what I came to you for. I came to you with a specific medical problem that you still have not addressed and that in itself is very, very frustrating. (Participant 13)

Women also told stories where providers failed to diagnose serious health conditions they presented with; they perceived that these providers were so repelled by their weights that they didn't investigate their complaints and therefore failed to diagnose these health problems. One woman stated, "If you go in with a headache it's because you are fat or something. If you go with anything it's because you're fat. Losing the weight solves all the problems for them, which it does sometimes. Sometimes it's not the weight, it's other problems but they can't find it because they can't seem to get past your weight." (Participant 15) Another woman also recalled times when she went to her provider with health problems but felt that her health conditions were not diagnosed. She recalled one encounter:

> I've gone to the doctor because my cycle wouldn't come on; the first thing they hollered was that I'm too big and I need to lose the weight and my cycle will come on, which wasn't the case…actually, I was pregnant; they never did give me a test to see that I was pregnant… um…I had another time when I had a …well a problem

> with my uterus and the doctor I saw said that I had too much fat around my uterus but that was not the case because when I left and went to another doctor, I found out exactly what was wrong and that doctor was able to take care of the problem. (Participant 6)

Other women also recounted stories where other conditions went undiagnosed. One woman spoke of making frequent visits to providers for a recurrent problem that providers failed to diagnose; she later found out that the cause of the recurrent problem was diabetes. Another woman reported having sleepless nights because providers would not address her sleep problem, attributing it to her weight. She finally found a provider who addressed the issue.

Many women also spoke of knowing their perceived risks for several chronic conditions because of their weights and described the ways that their health was affected by their weights. They wanted it known that they had this knowledge and did not want to be reminded with every healthcare visit. Several women talked about recognizing their risks. As this woman said:

> You're at risk for diabetes, heart disease, high blood pressure…personally my blood pressure has gone up and I know it's because of my weight…I mean stress may be related but I know my weight has a lot to do with it…I know…my cholesterol is up so…yes...and not being able to move…not being able to exercise as I want or I should do because I get tired easily and it's easier to sit down…I know that's not nice but that's the truth (laugh)…yes, it does slow you down but I'm always very conscious of the fact that I have too much weight on and that I'm at very high risk

because I have too much weight on. (Participant 4)

Another woman, the youngest of the participants, said:

> I know I have the risk for getting like heart disease and other illnesses. I try to eat right and exercise but I don't have any health problems…except that I was having the trouble with sleeping. Maybe it's because I have youth on my side but I know that the older I get, the more I may start having some health problems…I hate exercising. It's hard work. (Participant 12)

One woman who was diagnosed with diabetes said, "I have high blood pressure, I am what they call borderline diabetic, diagnosed last year, I can't…I get tired when I walk too much…short of breath…and my clothes don't look good on me anymore… so…yes, I've had problems since the weight." (Participant 14) This next woman admitted to "damaging her structure" and doing herself injustice. She recollected:

> I really have done myself a real injustice in that, because I was so big for so long, I damaged the structure…my structure …and therefore my framework has been the biggest problem for the last two or three years. My back and everything is just completely gone and I stay in just awful pain behind it…had one knee replaced and this was considered my good knee and now it needs to be replaced…um… I have gotten the age that I am and finding myself in a situation where I have problems, definitely got real problems going on…so, I don't know what I'm going to be in for, other than to try to take care of myself as much as I possibly can. (Participant 11)

The women addressed the fact that they were not oblivious to the health risks that their weights posed nor were they in denial of the consequences of being overweight. In fact, they welcomed discussions regarding weight management. What they resented were providers who continuously talked about their weights, instructed them to lose weight, but offered no help for them to initiate weight loss measures.

Theme #2: They Say Lose Weight but Give Us No Tools

Many women spoke of providers telling them that they needed to lose weight but not assisting them in doing so, not offering them the tools with which to help them lose weight. As one participant said:

> I am just another number to them so there is no particular interest in making sure…ensuring what are you actually doing…is there anything I can do to help, should I refer you…those are the things you kinda expect but most of the times you don't get that, can I refer you to somewhere that can help you lose the weight or what problems are you having with losing the weight. (Participant 4)

The women perceived providers' lack of care for them. One participant revealed, "They're not that interested in my well-being. I have never met a doctor yet that I thought was really interested in me and my well-being." (Participant 2)

Perceived lack of caring from providers was also expressed by other women in the study. As one woman said, "I'm…. it makes me feel like they don't care and um, um they just tell me….they just…you know…give me some information but you know…it's like they not really concerned; they just tell you….here are the facts. That's it." (Participant 12) Some women talked about providers who just did the bare essentials,

like lab values, but didn't inquire about their weight gain history and how they could best help the women achieve their goal weights. The provider's attitude was further perceived as uncaring when it was augmented by what the participant saw as poor demeanor and negative body language. This was conveyed by the following participant's story:

> I just felt like she was really short, straight to the point. It's really not what she said but how she said it to me. She said, look, your labs are okay but you are a risk factor for all these diseases and you have to lose weight, you have to lose weight. She didn't care to find out why I am in this situation and how she can best help me…you know…why did I gain weight, have I been this way all my life or is the weight gain recent…you know…You don't know my past and you are not taking the time to find out. It's her entire demeanor and tone, you know…her body language. (Participant 10)

Another woman who struggled with the fact that her health care provider never offered her the means with which she could lose weight described how she felt about the provider's lack of help:

> I would go to my primary care doctor and of course he would say Ms. (participant's name) you need to lose weight and stuff…and I know that…you know… I guess my struggle is the doctor never says, let's see could we come up with a weight loss program and what kinds of things would you like to do to help yourself lose weight…it's always, you need to lose weight. (Participant 2)

Many women felt that they were left alone by healthcare providers to figure out how best to achieve weight loss. They weren't happy with providers who consistently

told them they needed to lose weight but didn't take the time to educate them on how to do so or didn't offer pertinent resources. The inaction of the providers caused the women to believe that providers didn't care about them holistically. They talked about finding their own weight loss tools and resorting to the use of weight loss fads. The women wanted it known that they did not sit back and wait for resources to be offered but they took the initiative to find any and all sources of help, even though many were not successful in using these resources. This woman said:

> I follow all the fads out there…Try everything I've heard to lose weight…didn't work…'cause I'm no different than most people out there…you want it off yesterday so when it's taking forever, you lose trust in that one and try something else…and I've tried Jenny Craig, weight…no…what's the other one…um…um…quick weight loss…that's after I tried whatever on my own and um…I did sit in for one Weight Watchers class and gave up on that, okay. I just try things on my own…you know…just listen to the various things that people advise out there and try them. (Participant 4)

Another woman shared:

> Well, I diet, eat right…more vegetables…not so much carbs…drink a lot of water. I try to walk at the park down the road…you know…the one you passed down the street…but I get half way around the track and I get tired…I think one time around is one mile. I try to do that like three times a week but sometimes I don't make it the three times. I lost five pounds in the past month so I guess something is working (laugh). I want to lose about 80 to 100 more pounds and I'll be okay. (Participant

14)

Other women became emotional just talking about their pursuit of weight loss, the things they did in attempts to lose weight and their failure to achieve their goals or maintain the weight they lost. One woman started to cry when she spoke of looking at old pictures of her pre-weight gain times and wishing to be back at that weight. In her desperation, she talked about wanting to start taking weight loss drugs. The woman tearfully recounted:

> Um…I've tried to eat right. I have joined the gym. My brother is paying for membership but you know, it's hard sometimes to get to the gym. I do go but it is hard to be consistent and eating right, I don't think my portions are bad, I just think what I eat is bad. I am always busy so I eat a lot of fast food. I know that weight loss drugs are not good but I went to a weight loss center to get started on something….I am toying with the idea now of starting weight loss drugs because I feel like I need extra help to lose the weight and maybe I need an appetite suppressant but I know those are not good for me but I look at everyone else and I look at old pictures and I wanna get back to the way it used to be and…(She starts crying). (Participant10)

Instead of becoming emotional, other women simply accepted their weights. One woman spoke of trying to lose weight, not achieving her weight loss goal and deciding to just accept herself and the fact that her weight is what it is. She stated:

> I try to lose weight but it's easier said than done…I have tried. I have had a personal trainer and I have tried stuff but I still just fluctuate five to ten pounds but I've never

> lost like eighty pounds or something like that…I don't see any results so after a while you do less and you do less and you're the same weight…I'm not really sensitive about my weight… you know…I am who I am and this is who… this is it. I've worked on it and I haven't made progress. I'm good. I'm good with me…Basically, I've been the same weight for the last ten years…I'm good with that. (Participant 9)

While the women's earlier stories spoke of pervasive encounters of negative interactions with healthcare providers and of providers not offering them resources to help with their weight loss goals, the women recognized that they had some degree of personal responsibility in caring for themselves and in controlling their own weights. However, none of the women believed that providers should treat them negatively because of the provider's perception that obese women have total control over their weights.

Theme # 3: Stigmatization

This theme was pervasive across interviews and was, by far, the most salient discussed in the women's stories. Woven throughout the interviews were numerous stories of perceived stigmatization, where participants felt like they were treated negatively in various ways because of their weights. Stigmatizing encounters occurred in a variety of healthcare settings and with a diverse group of healthcare providers. Even so, participants' stories focused primarily on experiences with nurses and physicians. One woman recounted the experience she had when she had surgery for breast cancer and

her perception of stigmatization in the form of sub-standard care that she received. She said:

> …. this last experience here, with the breast cancer… um…the doctors that did my lumpectomy…my breast was leaking liquids, fluids. I was with my sister and she said, this is just not normal so we called and went back in and her words to me was, aah, I can't believe I forgot to put a drainage pump in there. I did not go back to see her again…she is the one who did the surgery so I did not go back to see her. I guess for me it's that…I feel that medically…that stigma again…is that you're overweight and just the whole problem is… so, you get sub-care. You don't get the top of the line; you don't get the top of the line. (Participant 13)

Other participants spoke of specific instances when healthcare providers treated them indifferently and made them feel inferior. The women recalled stories of the various ways that they were made to feel inferior and expressed how these encounters made them feel. One woman voiced, "It is really rough how people in health…the nurses and the doctors could treat you 'cause you are overweight. They tend to turn their noses up at you…like you are …you know…like you are crap." (Participant 6) She added:

> …and a lot of people don't choose to be overweight…you know…some, it's just in their genes, some can't help it…a lot of things you can help but it doesn't matter, if that person wants to be that way, that's who they are…they are clean. You can touch them. I'm almost sure nobody is going to go to see a doctor or other healthcare person …do a Pap being dirty…so don't look at them, like some doctors do, like they're nasty….I don't want to do that one today…and that's how some of them give

> you those types of nasty looks and feel when they come in the examination room with you. (Participant 6)

This was echoed by another participant who said:

> When I used to go to the county health department…um…I found that they look down on big women…you know… when you start taking your clothes off they behave like they were about to get knocked in the face with something. (Participant 1)

Talking specifically about being admitted in the hospital and the stigmatizing encounters she had with healthcare providers in the hospital, this same participant expressed the following, "When they have to do stuff for you, like change your bed or help you with stuff they behave like they don't want to do it, like if they come close to you or touch you, they will catch the disease of fatness." (Participant 1)

Other participants reported feeling saddened and overwhelmed following stigmatizing encounters. They professed high regard for healthcare providers and were disappointed and hurt when they encountered behaviors from healthcare providers that they perceived to be contrary to the training that healthcare providers receive. Some women spoke openly about losing respect for providers because of providers' negative treatment of them. This was evidenced in the following woman's story:

> I've had more than my share of medical personnel and the stigma, you know…just terrible, devastating. You know, you always grow up saying sticks and stones can break my bones but words will never hurt me……that does not….that doesn't fly…words do hurt…words do hurt and coming from people that you highly

> respect….you give nursing and medical personnel the highest respect because they work through a lot of schooling and training but there are just some who do not have people skills. (Participant 13)

Another participant stated, "I've had some real raunchy people, health professionals and …health professionals seem to think they have you over a barrel…and a lot of times they do, but there is no reason to treat people that way…my weight was…yes…a lot my doing…but whether that's the case or not, I deserve to be treated with respect, and anybody does…." (Participant 11)

Others perceive that providers were just "nasty" and had no valid reason to be that way to obese patients. This was evidenced in this woman's story, "They tend to give you a lot of nastiness for no apparent reason…and it's horrible… sometimes it depends on the individual. Some people don't need to be in nursing or healthcare….that's about it…you know." (Participant 6) This woman had been very ill and had been hospitalized multiple times in recent months so, for her, negative encounters were vivid. She continued to express one specific encounter she had where the implication made her feel like less than a human being. She recounted:

> … I messed my clothes and I couldn't get to cleaning myself completely by myself. I shouldn't have to wait till my mom or my husband get there to clean me…they're not my nurse…they're not my tech and if I buzzed you and ask you to please come and help me, that's your job…she went right outside talking loud…cause I guess because she thought she pulled the door up that I can't hear her….she was talking about me…dogging me out with others as if I am not a human

> being sick and in the hospital…you know…these are the types of things I've dealt with… I could be sick and throw up on myself and need help, they hesitate to change me or act indifferent when they do change me…they don't want to see my nakedness but they will change the person in the next bed with no problem… my bed may need changing and I have to wait a day or two before you can change mine or my mamma has to change it but the other person's gets changed when they need it. We have to literally demand for it to be done and it's horrible when you getting paid to do your job. (Participant 6)

Like this participant, another woman shared her experience while hospitalized and relayed one encounter she had with providers. The thought that healthcare providers talk negatively about patients when they believe that they cannot be heard by the patients was also a part of this participant's story. She stated, "I have had some experiences with some nurses that um…some of them don't realize that you can hear very well once they step outside that door and some of the things that have been said it's just…they have been very hurtful and ugly." (Participant 13) The following participant's story demonstrated one effect of negative treatment on obese persons and the unwillingness or inability of some obese persons to deal with such treatment, even if it means compromising their physical health. This participant recalled:

> I was treated badly on several occasions and addressed badly, talked to badly…um…even had situations where I had to walk out of my hospital setting. I had to let doctors go. I had rang for some assistance…um I didn't get anybody to

> come down and I walked out to the front desk …these nurses were discussing me and the thing that was so bad was that my doctor was among the nurses that were having a good time and discussing me …he was having a good time and laughing also with them. I immediately got myself together and I left…As I was going towards the elevator, he himself stopped me and I said no, no, no. I said, don't throw dirt on this grave…I said, you don't need me as your patient and I certainly don't need a doctor like you…I went on downstairs and I waited until somebody could come and get me. (Participant 11)

Other women recounted similar experiences. One participant recalled the indifference she encountered while hospitalized and interacting with nursing assistants. She recollected:

> You say you're in pain and they give you some medication…well the medication is not working is it possible for me to get something else…they say in a nasty tone or under their breath, I have to ask the nurse…you know…the techs…or when I was at a different hospital…you know…the gowns don't always fit, your behind is left bare and when I ask for a larger gown…because I know they have them or when I ask for a larger chair they don't reply when I ask but they may come back with it which made me know that they heard me…or they may not come back with it and I have to call several times. (Participant 1)

In a follow-up interview with another participant, a healthcare provider, she recalled a similar encounter of negative treatment while hospitalized for a knee replacement. The woman remembered calling for help to get up to her bedside commode, but receiving no help, she tried to get up on her own and fell to the floor. She spoke of the way the nursing staff interacted with her:

> I slipped and fell… I guess, the noise in my room caused two CNAs to come running. She proceeded to reprimand me for getting up on my own. She said it needed more than two of them to help me up. She walked out of the room to get more help and as she was at the door, I heard her say to the other CNA, she just won't listen…well, teach her a lesson to wait for help…She's going to stay there and wait until I get some more help. She came back with my nurse and two other CNAs. After I was assessed and helped back to bed, I asked for the nurse manager, reported the CNA and asks that she not care for me again. That was really the most demeaning treatment I've had from the nursing staff. (Participant 4)

Even though this participant seemed appalled by the behavior of this healthcare provider and felt the need to report her actions to the manager, she also communicated the belief that most healthcare providers don't really mean to cause intentional embarrassment to obese persons, although sometimes they do. The women spoke of the fact that while some healthcare providers may be deliberate in their negative treatment of obese persons, the majority do not set out to intentionally treat obese persons in a negative manner; however, such negative treatment occurs and when it does, obese persons are left with emotions that are injurious to them in multiple ways.

The majority of the women recounted multiple stories of negative treatment. However, three participants reported that they had not been treated negatively by their providers. Two of these women offered what they believed to be the reasons why their encounters with providers had been positive. One woman, a healthcare provider, explained her positive relationships with the providers who cared for her. She said:

> I have great respect for this person that's why I keep going. He is an excellent doctor. I worked with him for a long time and he takes good care of me. He manages all my health issues really well and I keep going to him…Actually I like the people who take care of me. I have working relationships with them as well and…you know…that kinda…I kinda think that makes the difference in how they treat me. (Participant 9)

Even though this participant never experienced negative treatment herself, she shared that in her work as a healthcare provider, she witnessed negative treatment of obese persons. She recalled:

> Some of the things that are said about obese patients are really not called for…you know, like she's too big, she just need to wait or if the trays are late…they might say something like, she doesn't need food anyway; she can live off of her fat or if they have to put like a Foley in they say really derogatory things about the woman. (Participant 9)

The second woman who shared that she had no negative encounters in healthcare settings was one of two women in the study who did not have health insurance. She revealed that because of her lack of health insurance, she only sought healthcare at times of her six

pregnancies. She attributed her lack of negative experiences to the fact that, not having health insurance, she really didn't go to providers frequently. Also, she had been seen in the same physician practice for all six pregnancies so they knew her well. More importantly, she believed that the ethnic make-up of the practice contributed significantly to the way she was treated. She stated:

> If my OB and the nurses were from a different descent, like Caucasian or Asian, you know….of course….that would have stood out and they may not have been as sensitive…thank God…my OB is an African American doctor, so are the nurses so maybe they are used to seeing women with that type of weight so we don't stand out. (Participant 5)

The last participant who denied being treated negatively by healthcare providers was very happy with her doctor. She described him as being "great" and someone she can talk to. She voiced that even when she was hospitalized, she got along well with the "girls," speaking of the nurses.

Along with negative physical encounters with healthcare providers that the women recalled, their stories also told of struggles trying to fit into gowns that didn't fit their bodies and on examination tables that were too small for them. In speaking of the inadequacy of the gowns, this woman said:

> Okay, my biggest thing in going to get mammograms in (name of hospital) where I had to change into these one size little tissue things that don't fit. They fit skinny people…those little paper gowns. It's like what size did you think it's supposed to be…you know… and they…they give you the little gowns and you gotta come out

> and sit with other people and then you got a gown on the front and a gown on the back because yours doesn't tie all the way around…that's another stigma. (Participant 13)

Another woman expressed her disappointment that healthcare providers she visited had not equipped their healthcare settings to reflect the increasing obesity in this country. She stated:

> I hate to squeeze in…not me per se but someone bigger than me…because I can still pretty much fit in the chairs in the waiting room but when I have gone with my sister, why should she have to stand because she can't fit comfortably in a chair in the waiting room or she has to change into a gown and it can't fit. I have problems fitting into the gowns and I am smaller than her. They need to be prepared. We have a lot of obesity…not just one race but all races so they need to have adequate things for larger people…for everybody…not one size fit all…It doesn't work that way anymore. Yeah, they need to have more than one size, chair, table, gown…all of them need to be bigger. (Participant 6)

While this participant believed that healthcare providers should be mindful of their environment and make it more adequate for obese persons, one woman addressed the fact that there are persons who are not that tolerant of providing accommodations for obese persons. She said, "Even though the gowns still fit me now, I have a hard time closing them…but you know…I've heard some people say, well, why they don't just lose weight so we won't have to accommodate them." (Participant 10) Other women spoke of

challenges they had trying to position themselves on the examination table. One woman recalled:

> It's not comfortable on the tables…the exam tables… sometimes I feel like I don't fit properly and I try to shift…I keep shifting myself in the center so that I don't feel like I'm falling off. (Participant 15)

Some women believed that even though they were uncomfortable with gowns that didn't fit them and examination tables that were too small for them, they had to accept them as the norm because they felt powerless to change them.

In this theme of stigma, women also discussed their perceptions that the care they received may have been influenced by certain characteristics of the provider, primarily the provider's gender, ethnicity and weight. Several women felt that when they were seen by female providers the care they received was more sensitive, gentle, and devoid of negative attitudes, whereas with male providers, the interactions were less sensitive and more stigmatizing. As one woman stated:

> The problem that I've had with obesity has mostly been with men. Men as health professionals are…they can't handle it. They don't have any…it's just straight-forward. They don't want to deal with women who are overweight…at all, not at all and the only reason that maybe they do, is because they have to…um…and that's what I found to be true. I don't know about others but all the incidents I talked about, all males. (Participant 11)

Another woman who said that she had stopped going to physicians many years before because of the negative treatment she received and had subsequently been diagnosed with breast cancer when she finally returned to a provider, spoke of the relief she felt at finally finding a provider whom she perceived cared about her and who listened to her. She raved about the provider, describing her as "just wonderful," saying:

> …I finally found a primary care physician who is starting to listen to me…finally. She is wonderful…but she is really a good caring person who looks out for my well-being. She is gentle, listens to me, doesn't make every problem a weight issue and lets me talk first and tell her what is going on with me. She is not condescending like some I've had in the past…doesn't behave like I'm inferior to her because of my weight…and all that means a lot to me. …anyway this doctor is wonderful and I would say the best experience I have had with providers. (Participant 13)

Others told stories of female providers who listened more attentively and were gentler in the way they performed pelvic examinations. In one participant's story she described the examination that a male provider did as "feeling like he was fixing an engine." In comparison, the female provider performed the same examination in a gentler and less painful manner.

Some women perceived the ethnicity of providers as contributory to the interactions these providers had with them. One participant recalled being hospitalized and spoke of the difference in ethnicities of her providers. She admitted to being treated better by African American providers and offered an explanation of what she believed to be a possible reason why providers of different ethnicities treated her badly. She said:

> The Black ones, the African American ones, they're cool but the other side…the other ones, they turn their noses up. They take their time to come and see about you…um…or what to do for you because you don't really need it…perhaps….you know…something like that. I guess it's because of their culture. They're not used to seeing or living with a lot of thick women…you know…they turn their nose up like they're better than you…like they couldn't be in your shoes one day. (Participant 6)

Another woman felt that even though White male providers had not blatantly said anything negative to her, they seemed reluctant to touch obese African American women. She noted:

> White males, they don't want to touch you, no…They'll just hide behind different things…just like…would you go on in and let her know I'll be there in a moment and stuff. Nurse would you have her…would you go on and check her temperature or something…but always making sure they still never touch you and if they do, they act like you got the AIDS virus and that it's just all dripping out of your eyeballs. (Participant 2)

Another woman admitted to always making it her priority to find providers who were African Americans. This woman, a healthcare provider, spoke of choosing healthcare providers based on the excellent care she observed them giving to patients but becoming disappointed when she made them her provider. She stated:

> I will always go out of my way to find a provider of my ethnicity because in the past I have not had what I thought was the best from the other…from another ethnicity.

> Working in the healthcare field, I have chosen doctors before based on the fact that they were so excellent with their patients on the floor and I went to see them and it was not so for me…and I perceive that it was not just …that it had something to do with the ethnicity of the person. I am a lot more comfortable with somebody who is of my ethnicity because…because I personally feel that I get better attention and as I said it's also based on what I've seen. I've seen the disparity in both and I know…I've seen it for myself. If I go in with a problem, it's treated differently from how the other race is treated… (Participant 4)

From the perspective of weight, several women perceived the weight of the provider to directly influence the way the provider treated them. As one woman said, "If you go to one that has a weight problem or they themselves are a little heavy or not a size five, they tend to…their office is…the whole set up is better, definitely…" (Participant 12) Another woman who had been having negative experiences with her provider, decided to see another provider, who happened to be overweight. She described the encounter:

> She was overweight and it was a totally different atmosphere…you know…she's always gentle when she does my exam…you know…the Pap test… she shares things she does to work on her weight…I feel like she cares about me….concerned about me as a person and not just wanting to degrade me because of my weight…she was real concerned about what was…she was listening hard…you know…after we talked, she did mention that she wanted me to exercise more, maybe try walking more…you know…and that would help bring down some of the pounds but she first

listened to the things that were wrong and tried to treat what was wrong and then the weight issue came up at the end as I was leaving. (Participant 12)

A few women in the study did not believe that the provider characteristics of ethnicity, gender and weight impacted the care given to them. For instance, one woman said, "It depends on who the individual is…to be honest with you. I haven't seen a difference in how they deal with me because of their weight…I think it is just who the provider is." (Participant 6)

Negative encounters as told in the stories of the women were many. Even though some women had positive encounters and were happy with their healthcare providers, the majority of the participants did not recall positive encounters. Not only did the women express emotional distress as they told of negative encounters, but they voiced disappointment at healthcare providers, whom they believed were trained to be sensitive to obese persons and "knew better." In addition, many participants were adamant that certain attributes of the provider like weight, gender and ethnicity were directly responsible for how that provider treated them.

Women who perceived that overweight providers treated them better than providers of normal weight expressed their belief that these providers, by virtue of their body sizes, were better able to relate to the obese woman and therefore more understanding of the discrimination that obese women experience. For women who said that they were treated better by female providers, their implication was that female providers had a greater propensity to being "human," were more apt to understand the plights of women, and had a gentler approach to care. African American providers were

thought to be more sensitive to obese women of their ethnicity. The women believed that this was so because the providers knew the culture and were more accepting of the fact that many African American women are full-figured.

Pattern # 2: Good Or Bad: It's My Decision

Two prominent themes comprised this pattern: Theme #1: Cancel My Appointment Please: I Won't Be Back, and Theme #2: Empowerment. The women spoke of the healthcare decisions they made in response to the encounters they had with healthcare providers. Even though they told of the various approaches used to avoid negative interactions with providers, the major outcome was avoidance of healthcare settings where negative attitudes were experienced. Frustration was a common feeling expressed among the participants who spoke of reasons why they made the decisions to stop going to a healthcare provider, changed to a new provider or delayed return to a particular provider. Some women also felt the need to use their weights as an avenue of empowerment for themselves and others.

Theme # 1: Cancel My Appointment Please: I Won't Be Back

This theme speaks to the women's stories of the ways they chose to avoid healthcare providers with whom they encountered negative treatment. While some women decided not to return for fear of being weighed, knowing that they had gained weight since the last visit, others made similar decisions because of perceived or actual negative encounters they had with providers. As one woman said:

> If I gained weight since my last visit and let's say it's like two weeks before my scheduled visit and I got on the scale…and if I gained weight, I'll call and reschedule to try to give myself time to get those pounds off because I just don't want to hear him complain, Ms. (Participant's name), you gained five pounds or Ms. (Participant's name) you gained ten pounds, or whatever…so I'll call and reschedule…(Participant 2)

Another woman also remembered an encounter where she delayed returning for care because was asked by the provider to lose weight and didn't accomplish that by the next appointment date. She expressed her fear that she would be unfairly classified as "non-compliant." She recalled:

> I didn't lose weight right away so when it was time for me to come back to him in three months…um…I didn't go back, because I wasn't ready for him to see me because I didn't lose the weight he wanted me to lose. I didn't lose the weight and I was afraid he would say that I was not compliant, even though I really tried. So I just felt like I'll just push it back, the appointment in another three months and hope that in that time I would have lost some weight. (Participant 15)

This participant's story was echoed by others:

> I knew I hadn't lost the weight so I didn't go back in three weeks. I stretch the return time for as long as I could because he is the type of person who, he works out, he runs marathons, he does all those types of things so when you go back…he even told me look…he went as far as to say, if you don't do what I ask you to do in order to control your weight…he said, I will drop you as a patient, so I didn't go back in

those three weeks because I knew I hadn't lost the weight. (Participant 7)

Several women spoke of times when they perceived such gross negative treatment from providers that, rather than subjecting themselves to continued stigmatization, they chose not to return to that provider. Many spoke of not only leaving providers who were negative to them but of not returning to any provider for many years and not getting Pap tests and mammograms. This woman spoke of being in such a situation, of literally giving up. She said:

> I change primary care physicians a lot because going in and explaining to them that I am not well….I am not feeling well…for someone to find a diagnosis that you just need to lose weight … I just didn't go. I simply just did not go back… literally, just gave up…whatever happens to this body was just going to happen. (Participant 13)

She continued her story by sharing her regrettable injurious physical outcome of not getting preventive healthcare for those many years. She added:

> If it had not had been for a…um… a young doctor…that I decide to just go…you know… I seen the sign saying, you know… OB/GYN and I think to myself, okay now (her name) you haven't been to no GYN in forever so I went to see her and she asked me about them cancer tests… she said, you haven't had a mammogram and if it hadn't been for her pushing me to go get all the different test, the colonoscopy and all that stuff, probably would not have found the breast cancer. I would not because….I wish I'd learned breast self exams...(Participant 13)

Other women spoke of similar encounters and of the challenges they had trying to find a gynecologist with whom they felt comfortable and who treated them in a positive manner. One woman expressed:

> She didn't even ask questions to dig further. It was just like okay, everything is fine but you know you have to lose weight…you know…her tone…treating me like a child and I know I'm twenty-eight; I'm still young but I'm an adult, not a child…I deal with so much discrimination all year round in different situations that I don't want to have a bad experience when I come to have those sensitive tests…It was like let's get this visit over with and let me go. (Participant 10)

Another woman spoke of being with her current gynecologist for several years but addressed the challenges she faced with other providers before finding her current provider. Following was her story:

> … I actually changed two providers…two gynecologists…before staying with the one I have now…and I have been with him now for over six years. The ones I had before, I felt like they were rough when they did my pelvic exam. One was really indifferent…I was very uncomfortable with him so I never went back. I didn't have a Pap for about four years. I found this other doctor but soon realize that he too was not very tolerant of full-figured women. (Participant 1)

In continuing her story, this woman remembered one particular incident that stayed vivid in her mind that frustrated her greatly and significantly contributed to her decision to delay getting essential preventive healthcare for gynecological cancers for many years:

> On the exam table he kept telling me to move to the edge but I was already at the edge and couldn't move any more. He kept asking me to spread my legs wider but I couldn't. It was frustrating and I guess he was frustrated …I said to him that my legs couldn't spread anymore and he said that if I wanted him to do the exam I had to open my legs because I was too big for him to examine properly. I asked him to stop, got dressed and left. I never went back to him. I never went back to anyone for several years, really…until my girlfriend forced me to go to the gynecologist I have now. (Participant 1)

One participant who was treated badly by her gynecologist and subsequently left that provider, admitted to missing her recent yearly Pap test and mammogram because she hadn't found a new provider to do her tests; she voiced being fearful of encountering the same negative experiences, saying, "**…** I haven't gone back to that gynecologist but I haven't seen anyone else since that one. I missed my annual exam this year because I don't know who to go to yet. I am trying to see if I can find one who someone can recommend because I don't want to have the same experiences I had before." (Participant 12) In emphasizing her disagreement with how obese women are treated in healthcare settings and the negative effects such treatment have on them, one woman shared the story of her best friend's daughter who had not had Pap tests and mammograms in seven years. She said:

> My girlfriend's daughter has not gone to have her Pap test and mammogram done in about seven years. She only goes to doctors when it is an emergency…she literally hates doctors because she had experiences of them discriminating against her

because of her weight…she is a very large girl…about three hundred and fifty pounds… I tried to get her to go see my gynecologist and her mother tried to get her to go see hers but I guess she just has no trust in them. (Participant 14)

Women also spoke of the emotional toll that negative encounters placed on them. One woman admitted to being very aware of the importance of getting her Pap tests and mammograms but of her delay in getting them done because she needed time to recover emotionally, after being treated negatively by providers. She said:

…I wouldn't say that they have stopped me from going back for them (Pap tests) because I know they are important but I have delayed going back because I feel like I need some time to recover emotionally before I go back to see a provider…I just need some time to recover emotionally… I wait a long time to go back because I just need some time so that I can recover emotionally before I go back. (Participant 15)

Provider "hopping" was also expressed by women in the study. They frequently changed providers so as not to encounter continued negative treatment. In this woman's story she addressed some of her reasons for her frequent change in providers. She recounted:

I tended to have changed providers several occasions because I've felt that you're not treating me right…you know…you are not taking my feelings into consideration…you know…just because I'm big doesn't mean that you can't do a proper Pap or ….I know I have a big chest but that don't mean you can't do a good mammogram or you can't teach me how to do proper breast cancer test…you know…it's still a chest and don't matter what size it is I can still feel for a lump…so

> I've had those experiences and when it has happened, I've told them, I don't appreciate how you make me feel and I won't return to them…. I will find me someone …'cause it's not right…it is discrimination because I'm a big girl and a lot of doctors do it. You shouldn't discriminate on any patient. You shouldn't discriminate at all. (Participant 6)

This woman continued her story by stating that not only did she change providers frequently but she delayed returning for Pap test because of discomfort with providers. She said:

> It will take me a while to go back for, especially a Pap test and it will take me a long while to feel comfortable about a new doctor, to have them do a Pap test…um…and I remember going with my sister to the doctor a while back …she is a lot larger than I am…and they discriminated against her so bad, she don't even like going to the doctor at all…you understand what I'm saying…so it's rough. It is really rough how people in health…the nurses and the doctors could treat you 'cause you are overweight. (Participant 6)

Stories of other women also revealed frequent provider changes. As the following woman's story conveyed:

> I came to the conclusion that he was just being downright rude. He was just being judgmental… he made me feel this small…rude… made me feel somewhat embarrassed and belittled but on the other hand it made me also feel…I was very intimidated by him …You don't want to go back to him because he doesn't really listen to you and you can tell by his attitude that he hates big people. (Participant 7)

Another woman who said she expected more from her provider but only received minimal care, with the provider focusing only on her weight and not addressing her other health issues, admitted to "packing it up." She stated, "Don't just say you need to go lose the weight, okay…pay more attention… yes it does affect my seeing the doctor because I am not losing the weight …so every time you go in you hear about your weight…I ended up packing up after a while…you can take that so long and no further…Common sense tells you…so I moved on." (Participant 4)

This important theme addressed the women's decisions to utilize healthcare services based on their encounters with healthcare providers (RQ2). As noted in the various stories, there was a plethora of emotions: embarrassment, frustration, powerlessness (giving up) and others, that were evident in the women's stories as a result of having to make decisions to delay care because of the provider's negative treatment.

Theme #2: Empowerment

Although women did not speak explicitly about being empowered or empowering others, many of their stories implicitly addressed the issue of empowerment, whether it was devising strategies to break the obesity cycle in their families, using their weights to teach others about obesity or exercising autonomy with healthcare providers when it came to decisions regarding their own or a family member's care. One woman spoke extensively of her quest to stop the cycle of obesity that existed among all the female members of her family. She told this story:

> …You can't close your eyes to it, it's there. It is just very blatant, just right there and you can see that our family has had this problem, ongoing all along so, we've got to

> do something about it. Because we have girls in the family and…then my little grand daughter…oh…I just made it up in my mind that I've got to do something about this while I can, so I started bringing the girls over here for the summer and I just work them to death…exercise and finding other things to do other than to eat…everybody play a game together. Let's stop looking at TV so much. Let's walk some. Let's go to the park…so now, for the summer I take them all…teaching them to observe some other health stuff that they need to…eating the right things…salads... knowing all the time that we can put good things in salads. We can put good fruit and vegetables. We can put things that we like, like nuts and stuff like that… hey, tomorrow we're going to walk to the library…We go to the gym. We get in the water…those kinds of things. (Participant 11)

This woman also told a story of having a gastric bypass surgery to help with her weight loss and recognizing that an intimate relationship she was in was abusive, "keeping her down," and based on excessive eating together. Like her quest to break the cycle of obesity in her family, she recognized the lethal nature of this relationship and its impact on her weight and felt empowered to end this relationship.

Others also told stories of situations that were empowering. They spoke of being autonomous in health care settings and feeling the need to direct their care or the care of a loved one to ensure the receipt of appropriate and sensitive care. As one woman said:

> I ask too many questions. I don't work as a healthcare provider but I have some medical background and they don't like it when I ask questions…even now when I take my daughter to the hospital and to the doctor…she has not been well for the past

> two years…you know…I find that the doctors and nurses get nervous every time when you ask questions and then take out a pen and a piece of paper and start writing. I kinda made one nervous who was tending to my daughter because he wasn't doing right by her and I spoke up and questioned him. He was being condescending to her, and focusing on her weight instead of asking her questions about the symptoms she was having that brought her to him…so I redirected him. (Participant 1)

One woman who had no health insurance spoke of being her own consultant and researching her symptoms before seeing a provider in order to be informed on what test to ask the provider to do to diagnose her problem. She stated:

> I don't have money to keep going from one doctor to the next so when I save up the money to go to the doctor, I want them to listen to me and try to help me. It's like two hundred dollars for one consult so when I spend that and they blow me off because they can't get past my weight I feel like I have wasted money … I don't have that kind of money to waste so I become my own consultant and diagnose myself. I say well, let me see what symptoms I am having and I try to read up on it. By the time I save the money to go to the doctor again, I can say to them, hey, this is what I am experiencing and here are the symptoms and I would like you to test for this, this, and this. You know, I try to go now with all the information that I can get about what's going on with me before I see them. (Participant 15)

Empowerment also manifested in the stories of the two participants who were nurses. They were asked about their stories as full-figured women working in healthcare

settings and interacting with patients. The women related how they used their weights to empower patients they encounter in their daily clinical practice. One, who talked earlier about being okay with herself as an overweight woman, said:

> What I do is use myself to teach my patients. I tell them what healthy eating is all about and the importance of exercise. I'll tell them about my sweet tooth and caution them to not start that habit. I tell them the risks of being overweight and I might tell them sometimes that I have high blood pressure that is directly attributed to my weight…so even though I am okay with me, I use me to let them know that if they are not yet overweight to stay away from being that way. (Participant 9)

The second woman admitted to "feeling bad" about being an overweight healthcare provider, believing that she should not be obese. Though implied, it seemed that she was feeling guilty and embarrassed because she saw herself as the one who should be educating others about the risks and consequences of obesity but instead, she was also obese. She told this story:

> It makes you feel bad. It really does make you feel bad because I'm thinking, I shouldn't be the one that's overweight, and so I feel bad, okay, for myself, I feel bad, but the way I use it as a positive is to…especially if I'm dealing with the younger people…is to use myself as an example of what not to be…not to be where I am and I'll teach them that you need to start from early. Pay attention to yourself. Don't just get caught up with the everyday running of doing this and doing that. Pay attention to yourself and don't let it slide…so I use me as an example to the younger ones of what not to be, in terms of weight. (Participant 4)

Empowerment was also evidenced in the women's need to be treated humanely and with respect, regardless of their body size. The women responded to a question asking them what they would like to tell healthcare providers about the way they want to be treated by them. Several women were very overt in verbalizing what they expected healthcare providers to do for them, how they wanted providers to treat them and what they found detestable. As this woman said in her story:

> … I would say take my medical history; listen to me. Listen to the symptoms that I'm having. Follow through with that. Make sure that those problems are taken care of and I understand that you want to talk about the issue of weight and that I do appreciate that you're concerned about that. I do not want that to be the very first thing out of your mouth. I come to see you and you want to know what's wrong and I start to tell you and your thing is what are you eating? What's your diet? That does not constitute a chest pain …That has nothing to do with my trouble breathing. It may be…it may be that I've got lung cancer…but I say treat what's wrong now and then we can work on the long term goal. Treat the short term goal now. Let's get me feeling better and then we could talk about the long term goal of getting me well… but I want to be well first. (Participant 13)

One woman who believed that healthcare providers don't usually take the time to get to know obese women wanted providers to know that, "Gaining weight is a sensitive situation for all women who are overweight. You don't want to be overweight. You don't wake up and say, I am going to be overweight." (Participant 7) Another woman said the following:

> It is a struggle for the person so try to be uplifting as opposed to you know, um…like putting the nail in the …you know…like turning the knife in the wound all the time 'cause it's a struggle for the person and, like I hear people say sometimes, I have a mirror. I don't need anybody to remind me all the time wherever I go because it's not doing any good, I think. (Participant 5)

Other women wanted healthcare providers to know that some overweight individuals do not have control over food and need help to not love food so much. This woman explained:

> …because if you ask ninety percent, maybe ninety-five percent of the people who are overweight I don't believe any of them would say they like to be overweight. I don't think some of them know how to not eat so much. Some of them don't know how to not love food so much. (Participant 7)

Another participant communicated her expectations of healthcare providers. She admitted to knowing that she had a weight problem and that she needed help with that issue; however, she felt that when she presented to a provider with an acute health problem, that problem should take precedence over her weight and should be addressed first by the provider. She requested of providers:

> I would say probably, I would like for you to treat my illness and what's wrong with me first before…I know that my weight may cause other issues but what I am coming to you for, if you would treat that issue first and then maybe we can get on some type of diet…you know...I want you to really look at what's wrong with me and what I'm complaining about now. I know that my weight may have caused this

> issue but I am having an issue right now…so help me fix this issue. I know that the weight did not come overnight and the problem that I am coming to you with just started …so if you can help me fix this problem, then we can get to the thing that I've tried to get rid of for the last 20 years…so…um…that's it. (Participant 8)

Participant 6, who had been ill and in the hospital recently wanted healthcare providers to know how she would have wanted to be treated by them. She started by saying, "…they'll discriminate against you 'cause of your weight…um…but your money spends just like everybody else's…" (Participant 6) She continued:

> Treat me like anybody else that's tiny or small that comes into your office 'cause we are all human beings. I'm a human being just like anybody else. Don't treat me like I'm the most disgusting person on earth just because I'm heavy…seriously…we have feelings too. (Participant 6)

The women were eager to let providers know that they had erred in their interactions with obese women and they wanted them to know how the errors could be corrected. This woman said, "I want you to treat me like you would treat your mamma. Full-figured people are not animals. I want to see us treated with compassion and feeling…um…I tell them like I tell my children, mind what you say to people cause it will come back to haunt you." (Participant 1) The analogy of "treating me like you treat your mama" was echoed by another woman, who said, "When I walk in the door, I don't care if I am a size five or a size fifty-five, treat me with same respect that you would your mother." (Participant 11)

Even though not as emphatic and detailed in their recommendations to healthcare providers on how they would like to be treated, other women also made their requests. One said, "I want to be treated just like you treat your other patients, provided that you treat them in a proper manner, okay. If I come in with an issue, I want the doctor to make certain that he or she orders the proper tests to determine what's going on." (Participant 2) Another said simply, "Don't treat me like I have a disease," (Participant 10) while one woman added, "…treat overweight women with the same respect that you treat other patients with. I wish all doctors and nurses could be like my doctor (doctor's name) and the nurses who work there…but they just need to be more careful and sensitive in the way they deal with overweight women…" (Participant 14)

This theme comprised the desperate need of the women to exercise autonomy and to be treated respectfully and appropriately by providers. The women suggested interventions that they believed would create a more amicable provider-patient relationship and spoke of measures they used to break the cycle of obesity. The emotional investment that some women made in suggesting these recommendations and the passion with which they spoke, were indicative of their genuine wish for providers to understand them and treat them as they would a patient who is of normal weight.

In this section we have discussed the results of this study. The lived experiences of obese African American women were presented in two patterns and five themes. The women shared stories of their daily lives living as obese women and utilizing healthcare services. The challenges they encountered and the decisions they made regarding those challenges, as well as the strengths they showed through these challenges, were evident

in these patterns and themes. The pervasive themes discussed centered on the women's perceptions that providers did not listen to them but blamed their weights for all health problems that they had. Also discussed was the women's viewpoint on certain attributes of providers (weight, ethnicity and gender) that they believed contributed to the way these providers treated them. The ways that women empowered themselves and others to manage their weights was also outlined in the study. In addition, recommendations that the women deemed pertinent for providers to know regarding how obese women should be treated in healthcare settings were described in this section.

Discussion

This study aimed to explore the experiences of obese African American women as they have utilized healthcare services. The sample of women described a wide array of experiences in healthcare settings that are supportive of previous findings that suggest a pervasive attitude of obesity stigmatization in healthcare (Berryman et al., 2006; Jeffrey & Kitto, 2006; Poon & Tarrant, 2008; Puhl & Heuer, 2009; Puhl et al., 2007). In general, the women felt that providers failed to listen to them, focusing on their weight rather than on the complaints that necessitated their visits. This was unsettling for the women as positive rapport could not be established. Rather than encountering discriminatory treatment, many women resorted to avoidance of healthcare.

Race, Gender and Stigmatization

Obesity stigmatization was found to be pervasive among the women in this study. However, before starting a discussion on the findings of the study, it is important to address the fact that just being "female," predisposes a woman to differences in treatment

in healthcare settings. Women do not always get the same quality of healthcare service as do their male counterparts. Many times, the care they get for various health conditions is sub-standard (Correa-de-Araujo et al., 2006; Daly et al., 2006; U. S. Department of Health and Human Services: Office of Women's Health [DHHS-OWH], 2007; Woods et al., 2006). When ethnicity is compounded with gender, it magnifies the problem.

African American women, by virtue of being in a minority group are already stigmatized. As reported by Smedley, Stith, & Nelson (2003) and Virnig et al. (2002), African Americans (AA) receive consistently poor care from HCPs for many conditions. With the interplay among gender, ethnicity and obesity, stigmatization of women who possess all three attributes, as do the women in this study, may be worse than is seen when only the attribute of obesity exists. Women in this study did not explicitly refer to their gender and race as directly impacting the care they received from healthcare providers, however, they spoke candidly about the providers' ethnicity and gender and their perception that these attributes of providers made a difference in the way they were treated.

Stigmatization: General

The women in this study reported that they experienced a plethora of negative attitudes from healthcare providers and were subjected at times to sub-standard health care and environmental obstacles. Hansoon (2010) had similar reports. Obese women in that study reported intimidation and inferior care from providers. Reports in this current study identified physicians and nurses as the main perpetrators of negative attitudes. Biased behaviors by nurses and physicians against obese persons have also been

described by other researchers (Fabricatore et al., 2005; Friedman, 2004; Jay et al., 2009; Martyn-Memeth et al., 2009; Vaidya, 2006). It is important to note at this point that while women in this current study reported both nurses and physicians as treating them negatively, physicians were often the most frequent perpetrators. This was also a concern in Hansoon (2010) where physicians were reported to be the source of more frequent negative behaviors. This may be attributed in part, to the fact that most people have more frequent use of physician services and physician-patient interactions than they do of nurse-patient interactions. Even though there are nurses in outpatient settings and physicians' offices, interactions with them may be fleeting and minimal. Usually, unless hospitalization occurs where the nurse-patient interaction is constant, obese women may have only infrequent or limited interactions with nurses.

Society, in general, holds the opinion that obese persons are the designers of their own poor health and so they are responsible for their own weights because they overeat and are slothful (Carr & Friedman, 2006; Puhl & Hueur, 2009). However, healthcare providers are widely regarded as advocates of all patients and are expected to be non-judgmental and non-discriminatory, regardless of a person's characteristics. As reported by these women, many healthcare providers treat them negatively because they perceive the cause of the individual's obesity to be lack of control by the obese person. Many individuals, including healthcare providers, believe that obese persons allow themselves to get that way by overeating and therefore, they have the ability to lose the weight if they choose to do so. This was brought out in the comments of one woman in the study who

reported an interaction with a provider in the Emergency Department who told her that she "let herself go and now wants everyone to jump and fetch."

In several studies, providers have reported their perceptions that unhealthy diet, physical inactivity and eating too much are the most salient risk factors of obesity, above and beyond biological, genetic and environmental factors (Bocquier et al., 2005; Brown & Thompson, 2007; Epstein & Ogden, 2005; Foster et al., 2003). Additionally, many healthcare providers perceive obese persons as lazy, stupid, having no self-control, lacking motivation, being non-compliant and responsible for their obesity (Bocquier et al., 2005; Brown et al., 2007; Hebl & Xu, 2001; Vallis et al., 2007). Because of these viewpoints, it is not inconceivable that providers might blame obese persons for gaining weight and therefore, be more apt to treat them negatively, as was reported in this study. Nevertheless, regardless of the reasons for a person's state of obesity, treating that individual negatively does not constitute sensitive healthcare delivery and may cause obese persons to use multiple strategies to counter the stigmatization that they frequently experience, including delaying their use of necessary preventive healthcare services, evidenced in this study.

Many women spoke of negative encounters they had with providers while hospitalized and the hateful things that have been said about them while they were at their most vulnerable state of health. The women expressed disappointment and disbelief at these occurrences and were upset that negative things were said about them while they were acutely ill.

Groups that are stigmatized, such as obese persons, are most often victims of discrimination and prejudice that may play integral roles in the perpetuation of health disparities (Stuber et al., 2008). This is particularly important to address because it has been reported that disparities occurring in healthcare because of stigmatization are very difficult to identify by healthcare systems (Dovidio et al., 2008). This may be because stigmatization in healthcare settings may be very covert by providers and not easily seen by persons in the healthcare system who are charged with ensuring quality of patient care and good customer service. From this perspective, the implication is clear: if disparities are created because obese women are stigmatized, then these disparities may go un-noticed, resulting in gross lack of health resources for obese women, and leading to perpetuation of obesity and further obesity stigmatization. This is a vicious cycle. Also detrimental to the stigmatized obese person is the risk for multiple psychological problems. Even though women in this study did not acknowledge any major psychological distress, weight stigmatization has been reported as a major risk factor for body dissatisfaction (Rosenberger, Henderson, & Grilo, 2006), depression (Friedman, Ashmore, & Applegate, 2008; Jackson, Grilo, & Masheb, 2000) and low self-esteem (Annis, Cash, & Hrabosky, 2004).

Stigmatization: Environmental Inadequacies

Trying to get gowns to fit and getting positioned on examination tables were particularly challenging for the women. Several women felt stigmatized because providers did not expend the time or effort to equip their facilities with adequately sized gowns and examination tables that could accommodate larger women. Others

complained about blood pressure cuffs that were too small for their arms while others felt that chairs in the waiting rooms didn't always accommodate them. These findings of environmental inadequacies were consistent with reports by others (Kaminsky & Gadaleta, 2002; Merrill & Grassley, 2008; Pryor, 2002). The women felt that providers thought it easier for obese women to lose weight than for providers to make the necessary changes to accommodate larger women. While the obesity rate in the United States has indeed escalated and some individuals may be insensitive to this population, obese persons are consumers of healthcare just as much as persons of normal weight and should be just as comfortable in the healthcare environment as other persons are.

Stigmatization: Provider Characteristics

Even with the reports of negative attitudes that were persistent among the women, a few women reported having no negative experiences with healthcare providers and were complimentary of the care they received. Similar findings were noted in Thomas, Hyde, Karunarante, Herbert, Komesaroff, (2008) where obese women reported positive encounters with providers and believed that providers advocated for their care. Thomas et al. (2008) did not offer a reason for the women's experiences, but in this current study, the women all attributed their positive experiences to the fact that the providers were either overweight, of the same ethnic culture as the women, or were females. One woman in the current study attributed her positive experience to the fact that she was also a healthcare provider and had good working relationships with her providers.

Reports of positive treatment of obese women by female providers were pervasive. The best and most memorable provider encounters that the women recalled

were those that they had with female providers. Many described these encounters, and a common view was that female providers were gentler, more sensitive and caring and less negative than their male counterparts. This finding parallels the reports of several studies that found male providers to be more stigmatizing of obesity than female providers (Hebl, Ruggs, Singletary, & Beal, 2008; Latner, O'Brien, Durso, Brinkman, & MacDonald 2008; O'Brien et al., 2008; Puhl et al., 2005). Two women in this current study did not perceive a difference in the way they were treated based on these characteristics of the provider and attributed the provider's negative treatment of them to that provider's personality and specific beliefs about obesity.

As expressed in the stories of the women, while there were providers who exhibited positive attitudes toward obese persons, many providers seemed to have disgust for persons who are obese. The vivid stories of the women demonstrate that there are those providers who continue to exhibit negative behaviors toward them because of their weights. The women's stories reflect the lack of obesity sensitivity among some providers. It is very important, and an accepted standard of healthcare, that healthcare providers provide care that is holistic in nature and that addresses all aspects of health with individuals. The women in this study want it known that obese women do not appreciate interactions with providers that are stigmatizing. They want to be listened to and afforded positive care. As Participant 1 said, "treat me like you treat your mamma." Obese women want to have discussions about health and weight with their providers but they ask that those discussions be done in a respectful, non-embarrassing, and non-judgmental manner. This was not always the case, as was reported by many women in

this study. Merrill & Grassley (2008) also noted that women frequently received poor care and perceived debasing and embarrassing interactions from providers.

Delaying Care

Similar to the findings in other studies (Amy et al., 2006; Ferrante et al., 2006; Howe, 2006; Wee et al., 2000), women in this study reported delays in getting preventive healthcare for Pap smears and mammogram screens; some reported not having these tests in as many as seven years. The story of one woman, who was diagnosed with breast cancer after years of not going to a provider, but eventually mustered the courage to go, was testament to the deleterious consequences that are possible when women are deterred from getting timely preventive health screens because of intolerable, stigmatizing attitudes they encounter in healthcare settings.

Even though women in this study reported delays in getting both types of screens, delays in getting Pap smear screens were reported more frequently than delays in getting mammograms. This was also a finding in Ferrante et al., (2006) and Ludman et al. (2010). Although Cohen et al. (2008) noted that there were no delays in breast cancer screening among obese African American women, this study supports others who showed that about 64% of obese women compared to 35% of non-obese women delayed their return for follow-up care for abnormal mammograms. Women in this and other studies did not explicitly state reasons for delaying their Pap smear screens and mammograms; however, it can be assumed that the invasive nature of Pap tests and the impersonal body position that a woman must assume to have this test done, may be contributing factors. Moreover, when women perceive that providers perform the test in a rough manner, are

demeaning, speak rudely to them or display negative non-verbal cues, women may be more likely to delay having these tests performed. In addition, since mammograms may be perceived as less invasive than Pap smears, women may be more apt to have more mammograms done than Pap screens. Another important reason why women may have greater delays in getting Pap test than they do for mammograms, is the fact that even though mammograms are done by HCPs, they are not done by physicians.

Also contributing to the women's delay in getting mammograms and Pap smear screens is the reluctance of some physicians to perform this test on women who are obese. Consistent with Ferrante et al. (2006), who reported that physicians were reluctant to perform Pap smear screens on very obese women, women in this study reported that some physicians were unwilling or not eager to perform Pap smear screens on them. This was seen in the report of one woman in this study whose provider told her that he would not do her Pap test because she was too big and he would not be able to perform the test. Like the findings in Ferrante (2006), this study demonstrates that physicians may be reluctant to perform Pap smear screens on women who were larger (BMIs $\geq$40). This may be due to the provider's inexperience in doing Pap screens on obese women, or the perception of the provider that doing the screen will take a longer than normal time to perform. Whatever the cause of the provider's reluctance, it is perceived as stigmatization by obese women.

Findings of this study also indicate that not only do obese women delay visits to providers for preventive care when they perceive negative treatment, they are also reluctant to return to any provider who treats them negatively. The women in this study

indicated that they would rather suffer their physical symptoms and wait until they find a provider who treats them in a positive manner than return to one who is demeaning and who makes them feel like, as one participant stated, "less than human." As has been suggested, when bias is introduced in healthcare settings, some individuals may react negatively and greater risk of healthcare avoidance may occur (Brownell et al., 2005). This was the overwhelming report of women in this study.

Some women in this study have also reported walking out of hospitals without getting proper medical discharge because of stigmatizing treatment. Merrill & Grassley (2008) noted similar encounters, where one obese woman remembered, delivering her son and how hurt she felt in the delivery room when the physician told her to relax and envision herself on a beach like a big ole whale. It is difficult to comprehend that this provider's goal, as well as the reported actions of the providers in this current study, was to embarrass, belittle or deter the individual from continued healthcare; one would want to think that the aim was merely to calm this woman's fear of child-birth and relieve her anxiety. However, this demonstrates the insensitive nature of some providers who do not take a brief moment to stop and think how their insensitivity and possible negative beliefs about weight might hurt the obese woman and impact her decisions to return for care. Other women in this current study had a ploy of calling and rescheduling appointments if they had not lost weight since the last visit, while others called and cancelled their appointment all-together, without remaking a new one. They reported fear of being weighed, of being embarrassed, or of being reprimanded by their providers for their lack

of weight loss, even though they knew they had tried desperately to lose weight. Other studies had similar findings (Ostbyte et al., 2005; Olson, et al., 1994).

Along with the delay in seeking healthcare that was reported by many participants in the current study, several admitted to changing providers frequently and not staying with a provider until they were absolutely sure that they would not be subjected to negative attitudes. The emotional toll that stigmatization takes on obese women can be enormous, as seen in the comments of Participant 15 who felt that after negative treatment from a provider, she needed time to recover emotionally before returning for female kinds of tests.

As noted by Participant 8, if healthcare providers do not treat obese women well, then the women have choices and can go elsewhere. She is correct. However, the problem is that physician "hopping" can be potentially injurious to the health of obese women. Switching providers may not be done in a timely manner, as women may take quite some time to carefully find a new provider who possesses the attributes they seek. In addition, once a new provider is found, it may take the obese woman a long time to get acclimated to the new provider, to the point where she is comfortable and trusting enough to allow that provider to do sensitive preventive health screens. To that end, the ideal situation is for obese women to be entirely comfortable with their providers and have complete trust in them so that excellent rapport can be built and timely healthcare can be sought without reservations.

Not Listening: Blaming Weight

Consistent with other reports (Amy et al., 2006; Anderson & Wadden, 2004;Brown et al., 2006; Merrill & Grassley, 2008), the women in this study recalled multiple episodes where they perceived that providers did not listen to them, instead telling them that the symptoms they were experiencing were directly related to their weights. This was particularly frustrating for the women who recognized the provider as the expert in healthcare but also knew that the symptoms they were experiencing in their own bodies were real. This was evident in the comment of Participant 9 who so vividly described encounters where she had gone to providers with migraine headaches or the flu and the provider's first recommendation, without doing an examination, was for her to lose weight. The obvious disinterest of the provider in giving validity to the women's complaints and blaming their weight for all problems presented a major barrier to communication between both parties. These findings suggest that some providers have difficulty legitimizing obesity and their inability to accept it as a condition that is more than just "the obese person's fault" hinders them from taking the complaints of the obese person seriously.

The women in this study were aware that while weight loss can be advantageous to the health of a person who is obese and may certainly improve physical, psychological and social health, weight loss discussions must be put in the correct context by healthcare providers. They felt that obese individuals, who are in an acute health crisis, necessitating immediate treatment to prevent compromised health, do not need to be given a lecture on how obese they are. Also problematic was the report that some

providers failed to diagnose serious conditions because they focused on the women's weight and could not move beyond the weight to do a thorough assessment and order the correct tests to diagnose their problems. As women in this study spoke about this particular issue, their frustrations were evident. However, even more transparent was the pain that these encounters caused them. It was not uncommon for the women to start crying when they recalled such encounters. This was not a unique finding in this study because this was also reported in Merrill & Grassley (2008) where one woman reported that her polycystic ovarian syndrome was not readily diagnosed because the first physician she visited focused on her weight and diet and did not address her presenting symptoms.

It is not difficult to imagine how these interactions can cause obese women to feel inadequate and unimportant in healthcare settings and to perceive lack of care on the parts of providers. Moreover, it is conceivable that women who feel like their healthcare providers do not give them the attention they seek, or listen attentively to their problems, will seek care elsewhere or become so deterred from interacting with healthcare providers that they may not ever return for necessary and timely preventive healthcare.

Empowerment: Knowing Risks and Consequences

Also impacting the women's utilization of healthcare services was the report that healthcare providers consistently told them to lose weight but gave them no resources with which to help them start the process. The inaction of the providers deterred many of them from going back to that provider but they did not remain passive; they were empowered enough to explore avenues of weight loss on their own, resorting to all the

latest weight loss fads. This is important action on the part of the women because it helps to refute the findings of other studies (Bocquier et al., 2005; Brown et al., 2007; Hebl & Xu, 2001; Vallis et al., 2007) where obese women were reported to be lazy. The fact that these women recognized the need to lose weight and initiated their own weight loss strategies, when providers failed to help them, is testament to the fact that obese women are not lacking in self-will. Instead, many are usually autonomous in their own care. Equally impressive, was the fact that some women in this study used their weights as examples to empower others to change and to teach other women the importance of taking care of themselves and doing all that is within their control to remain at normal weights. In this study, empowerment is an important theme. We believe this to be the first study where obese African American women have reported using their weights to empower others.

Women were asked about their perceptions of their risks for chronic health conditions because of their weights and whether their health was adversely affected because of their weights. They all reported at least two major health conditions that could be attributed to their weights. Obese women are thus not ignorant of the consequences of obesity and are not resentful toward healthcare providers who address their weight at the time they address other health conditions. However, obese women do not want their weight to be the first, or the only thing, that providers address when they go to them for care. They are cognizant of the detrimental effects of being obese and welcome education and treatment from providers. What they do not welcome is negative

and insensitive interactions or providers who badger them continuously about their weights instead of addressing the issue for which they have sought care.

Finally, The Interaction Model of Client Health Behavior [IMCHB] (Cox 1982) helped to frame the assumptions for this study (discussed in Chapter II). The model proposes that the HCP's interaction style and approach toward clients has the ability to support or discourage the client's health behaviors. A primary assumption of this study was that obese African American women would recount negative interactions with healthcare providers and would report delay in utilizing health care services, specifically preventive care, because of their experiences. This assumption was supported as reports of negative encounters with healthcare providers were pervasive in this sample of obese women. The women reported that they often delayed returning for care because of their negative interactions with providers. They described the ways in which they delayed care, often with unfavorable outcomes. Another assumption of the study was that larger women, that is, women with BMIs over 40, would have more dramatic and frequent encounters of stigmatization. This assumption was based on other reports where women with moderate to severe obesity reported higher levels of mal-treatment and more negative comments from providers (Carr & Friedman , 2005; Hansson , 2010; Huizinga, Cooper, Bleich, Clark, & Beach, 2009; Puhl & Brownell, 2006). The stories of women in this study supported this assumption. Women with higher BMIs ($\geq$ 40) in this study reported more stigmatizing episodes from healthcare providers than women with lower BMIs.

Study Limitations

There are several limitations of this study. First, weights and heights were self reported. Usually, persons who are overweight have the tendency to underestimate their weights and over estimate their heights, presenting the potential for inaccurate BMIs. However, because this was a qualitative study, with face to face individual interviews, the researcher had the opportunity to visualize all participants. Even though one should not be reliant on visualization alone to determine an individual's weight status, looking at someone can help to appreciate the person's possible weight. This was the case in this study. Once the researcher saw each participant, it was evident that their body sizes met the weight inclusion criterion.

Second, the recruitment strategy of the study and the fact that participants responded to posted flyers and selected themselves to be in the study may have added some degree of bias to the study. It may be argued that participants who agreed to be in the study were those who encountered the most negativity in healthcare settings and therefore had stronger viewpoints that they were very eager to talk about. However, this was not found to be the case as some women spoke of having providers who did not discriminate against them and with whom they had good relationships. Third, this was a fairly educated sample with most women having graduated from college or having some college education. While the stories of these women are valuable to the understanding of the experiences that obese African American have on a daily basis, it may be difficult to transfer findings of this study to obese women of lower educational levels.

Finally, although there were limitations, a major strength of the study was the fact that the sample was comprised of only African Americans. Multiple studies of this issue have been conducted with populations of Caucasian and other non-African American persons, leaving a gap in the knowledge regarding African American women, a gap that has been partially filled by this current study. Results of this study are similar to previous studies, but differences were also identified. For instance, as in previous studies, women in this study recalled the same types of negative encounters with providers and reported similar avoidance of healthcare because of their encounters. However, unlike other studies, empowerment of self and others was expressed by women in this study. This finding of empowerment has not been previously reported in studies of obese women.

Summary

In summary, this chapter presented the findings of the study and reported the stories of obese African American women as they utilize healthcare services. The salient patterns and themes that emerged from the women's stories were clearly presented in this chapter, along with very vivid narratives of the women's' stories. A discussion of the findings was also outlined and the similarities and differences to previous studies were delineated. The chapter also addressed the study's limitations and strengths.

CHAPTER VI

Conclusions and Recommendations

Data from this study suggest that stigmatization of obese women is pervasive in healthcare settings. It is not surprising that healthcare providers treat obese women negatively since other studies have had had similar findings. However, the women's experiences present important implications for their quality of health and future health care utilization. The women in this study experienced a multitude of stigmatizing encounters while trying to utilize healthcare services. They perceived these encounters to be offensive and demeaning and felt that providers were not supportive. These perceptions resulted in the women avoiding providers, especially for sensitive female tests like Pap smear screens and mammograms. At times, their delay in getting healthcare resulted in injurious physical health consequences.

The women detailed the types of negative encounters they experienced, the impact it had on them both physically and emotionally, and how they felt about these encounters. They wanted to dispel the common existing perception that obese persons are lazy. The women were careful to describe the strategies they used to attempt weight loss and the various ways they empowered others to maintain healthy weights.

Overall, the study demonstrated that obese women are eager to have relationships with healthcare providers that are meaningful and mutually positive. They recognize that delaying healthcare for preventive health screens is potentially detrimental to their future

health but perceive the avoidance as being better than subjecting themselves to stigmatizing behaviors of providers. The fact that obese women delay returning for healthcare, primarily preventive healthcare, is problematic because of the significant association between obesity mortality from cervical and breast cancers (Calle et al., 2003; Stolley et al., 2009). Because of the prevalence of obesity in women in the United States, it is of utmost importance that obese women increase their timeliness for Pap smear screens and mammograms.

Implications for Clinical Practice, Education, Policy, and Research

A non-judgmental and sensitive approach in the care of obese persons is essential if obese women are to be expected to seek timely preventive healthcare. The common perception that obese persons can readily control their weights but choose not to do so not only exists in the general population but is pervasive among health care providers. It is this mentality that contributes to the negative treatment that many women report when they utilize healthcare services. Therefore, in clinical practice, providers may need to reassess their attitudes toward obese persons and assume a position of neutrality when interacting with these individuals. Their biases regarding obesity should be set aside as they recognize that the healthcare needs of obese persons supersede the issue of weight. This is a particularly important recommendation, as a common comment that women made in the study was that providers frequently ignored their acute health condition, focusing instead on their weights. Additionally, in clinical practice, healthcare providers need to foster an environment of positive care, open communication and empathy when interacting with obese women.

Women in the study felt that some healthcare providers they encountered needed to get obesity sensitivity training and questioned whether these providers ever had such education as they were being trained to become health care providers. In light of the increased prevalence of obesity nationally, one recommendation of this study that would be beneficial to the relationships between obese persons and health care providers would be the initiation of focused obesity sensitivity training either in college curricula of healthcare programs or early in the practicing roles of these providers. Among the areas of training, curricula might incorporate beliefs and attitudes about obesity, sensitive and therapeutic communication with obese persons, and identifying, developing or prescribing weight loss resources for obese individuals. Since the beliefs of some providers about obese persons, and their subsequent negative treatment of these individuals may already be embedded in their personalities, it may be difficult to suggest that providers just "simply change" their ingrained habits. Therefore, for providers who are in practicing roles, facilities for which they are employed, should offer periodic "refresher" training focused on obesity stigma reduction and sensitive care of obese persons. Maclean et al. (2009) had similar recommendations.

From a health policy perspective, obese persons have no recourse when they encounter discrimination in healthcare settings, or any other area. Therefore, at both state and federal levels, policy makers should ensure that there are legal means to protect obese persons against weight discrimination. Except for the state of Michigan which has prohibition of discrimination based on weight, no other state has any such law. Even so, Michigan's weight law only protects the obese person in employment. A few other

states, or some cities in these states (District of Columbia & San Francisco), have ordinances that include body sizes. Absence of obesity discrimination laws poses major problems for obese persons as there is no legal remedy if they are unjustly discriminated against.

Finally, future research should examine the health consequences of obesity and the role that stigma plays in these consequences. Stigma reduction intervention studies might be beneficial in alleviating the pervasive stigma in healthcare settings. Very few such studies have been conducted. O'Brien et al. (2008) was able to use a stigma reduction intervention in a sample of health service students; findings in the study showed that such an intervention can reduce obesity stigma. Puhl et al. (2005) in an intervention study also found that stigma reduction interventions can be used to change perceptions of obesity and decrease obesity stigmatization. Therefore, continued intervention studies are needed to fill the gap in knowledge.

In addition, since this study was conducted from the perspective of the "patient," and reports of stigmatization were from the perspective of the patient only, future studies from the viewpoint of the healthcare provider are recommended. Hearing stories from both the patient and the provider may enlighten the reader on any differences or similarities between perspectives of the patient and the provider, clarify possible misunderstandings, and resolve major problems.

Summary

In summary, the experiences of obese African American women remain insufficiently explored. This study explored women's experiences of being obese, using

a qualitative approach. This method was deemed the most helpful in providing a richer insight into the women's experiences than that revealed when pre-existing measurement instruments are used. While studies have been conducted examining the issue of obesity from the perspective of stigmatization and healthcare utilization, very few have examined the issue from the perspective of African American women. Studies conducted have largely comprised Caucasian women. This study provides additional support for the need to focus on issues of obesity among a specified, at risk population. It is hoped that the study will increase the awareness that negative attitudes toward women who are obese, specifically African American women, the group most affected, exist. Obese women need to be cared for by providers who are educated on issues of obesity, empathetic to the plight of obese women and are willing to provide sensitive and non-discriminatory health care. This includes listening attentively to the health problems of the obese woman who presents to the provider, refraining from attributing all health problems to weight, and ensuring that the healthcare environment is outfitted with "weight-friendly" equipment.

Essentially, focusing on the healthcare needs of the obese woman and not on her size may help to ameliorate the poor relationships that exist between many obese women and their healthcare providers. Perchance, the ultimate result may be that obese women will be less fearful and less reluctant to seek preventive healthcare services. Finally, even though it is reported that obese persons have greater utilization of healthcare services (Barrett et al., 2008; Raebel, 2004; Wolf et al., 2008), these studies show that utilization is primarily attributed to the health consequences of obesity (i.e., diabetes, heart disease)

and to emergency care (Gullar-Castillion et al., 2002) and not for preventive screens. Therefore, the findings in these studies support the need for this current research.

Ruhm (2007) reports the staggering rate at which obesity in women will increase in the ensuing years. If past and present obesity trends hold true, obesity will be an even greater societal dilemma than it is currently. With this in mind, every approach should be taken to minimize the detrimental consequences of obesity. This study highlighted the issue of stigmatization of obese women in healthcare settings. Obese women who perceive that they are being stigmatized when they seek healthcare may avoid healthcare providers, as was reported in this study. With the predicted exponential increase in obesity and the known illnesses that are attributed to obesity, it is very easy to imagine that these illnesses will also increase. Seeking timely healthcare to prevent illnesses associated with obesity will be a priority for obese persons. Therefore, if the deleterious consequences of obesity are to be reduced or prevented, obese women must feel comfortable with healthcare providers and must be assured that they will receive non-discriminatory health care.

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Appendix A

Institution Review Board Approval – Georgia State University

Georgia State University

Appendix A

INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
Atlanta, Georgia 30302-3999

In Person: Alumni Hall
30 Courtland St, Suite 217

Phone: 404/413-3500

Fax: 404/413-3504

July 1, 2010

Principal Investigator: Moloney, Margaret F

Student PI: Winsome Stephenson

Protocol Department: B.F. Lewis School of Nursing

Protocol Title: Experiences of Obese African American Women as They have Utilized Healthcare Services: The Influence of their Experience on Utilization of Preventative Healthcare Services

Submission Type: Protocol H10518

Review Type: Expedited Review

Approval Date: June 30, 2010

Expiration Date: June 29, 2011

The Georgia State University Institutional Review Board (IRB) reviewed and approved the above referenced study and enclosed Informed Consent Document(s) in accordance with the Department of Health and Human Services. The approval period is listed above.

Federal regulations require researchers to follow specific procedures in a timely manner. For the protection of all concerned, the IRB calls your attention to the following obligations that you have as Principal Investigator of this study.

1. When the study is completed, a Study Closure Report must be submitted to the IRB.

2. For any research that is conducted beyond the one-year approval period, you must submit a Renewal Application 30 days prior to the approval period expiration. As a courtesy, an email reminder is sent to the Principal Investigator approximately two months prior to the expiration of the study. However, failure to receive an email reminder does not negate your responsibility to submit a Renewal Application. In addition, failure to return the Renewal Application by its due date must result in an automatic termination of this study. Reinstatement can only be granted following resubmission of the study to the IRB.

3. Any adverse event or problem occurring as a result of participation in this study must be reported immediately to the IRB using the Adverse Event Form.

4. Principal investigators are responsible for ensuring that informed consent is obtained and that no human subject will be involved in the research prior to obtaining informed consent. Ensure that each person giving consent is provided with a copy of the Informed Consent Form (ICF). The ICF used must be the one reviewed and approved by the IRB; the approval dates of the IRB review are stamped on each page of the ICF. Copy and use the stamped ICF for the coming year. Maintain a single copy of the approved ICF in your files for this study. However, a waiver to obtain informed consent may be granted by the IRB as outlined in 45CFR46.116(d).

All of the above referenced forms are available online at https://irbwise.gsu.edu. Please do not hesitate to contact Susan Vogtner in the Office of Research Integrity (404-413-3500) if you have any questions or concerns.

Sincerely,

Susan K. Laury

Susan Laury, IRB Chair

Federal Wide Assurance Number: 00000129

Appendix B

Institution Review Board Approval-Mercer University

Appendix B

MERCER UNIVERSITY
Institutional Review Board
for Research Involving Human Subjects

13-Jul-2010

Ms. Winsome Stephenson
Mercer University
Georgia Baptist School of Nursing
3001 Mercer University Drive
Atlanta, GA 30341

RE: The Experiences of Obese African American Women as they have Utilized Healthcare Sercices: The influence of their Experiences on Utilization of Preventive Healthcare Services that Detect Breast and Gynecological Cancers (H1007153

Dear Ms. Stephenson:

Your application entitled: "The Experiences of Obese African American Women as they have Utilized Healthcare Sercices: The influence of their Experiences on Utilization of Preventive Healthcare Services that Detect Breast and Gynecological Cancers" (H1007153 was reviewed by this Institutional Review Board for Human Subjects Research in accordance with Federal Regulations 21 CFR 56.110(b) and 45 CFR 46.110(b) (for expedited review) and was approved under Category 7 per 63 FR 60364.

Your application was approved for one year of study on 12-Jul-2010. The protocol expires 12-Jul-2011. If the study continues beyond one year, it must be re-evaluated by the IRB Committee.

New Application

Please complete the survey for the IRB and the Office of Research Compliance. To access the survey, click on the following link:
http://www.zoomerang.com/Survey/?p=WEB227URK2RB6Q

It has been a pleasure to work with you and much success with your project!!

If you need any further assistance, please feel free to contact our office.

Mercer University IRB & Office of Research Compliance
Phone (478) 301-4101
Fax (478) 301-2329
ORC_Mercer@Mercer.Edu

Respectfully,

Ajuania White

Ajuania G. White, MPH, CHES, CIM
Member
Instutional Review Board

AGW/acr

Appendix C

Consent Form

Appendix C

GEORGIA STATE UNIVERSITY

BYRDINE F. LEWIS SCHOOL OF NURSING

Informed Consent

Title: Experiences of Obese African American Women as they have Utilized Healthcare Services: Influence of the Experiences on Utilization of Preventive Healthcare Services

Principal Investigator: Margaret Moloney, RN, PhD, ANP

Student Investigator: Winsome Stephenson, RN, MS, PhD (c)

Introduction/Purpose:

You are invited to take part in a research study. The purpose of this study is to learn more about the experiences of obese African American women as they have used healthcare services. We hope to understand how their experiences determine their use of healthcare screens for breast and cervical cancers. You are invited to take part because you are an African American woman who is overweight. A total of 15 women will be recruited for this study. We expect that this study will take about 10 months. Participation in the study should take no more than a total of 2 hours.

Procedures:

If you decide to take part, you will be asked to sign a consent form before you start the study. Ms. Stephenson, the student researcher, will conduct an interview with you at the location that was agreed upon when you first spoke with her. You will have contact with only one researcher. The interview will take place sometime during the months of June-November. The purpose of this interview is to hear your thoughts about the experiences you have had when you have sought healthcare. You may be asked to do a second interview. The second interview is to clarify any information from your first interview. This second interview will be within one month of the first. Both interviews will be at a time and place that is agreed upon by both you and the researcher. Both interviews will be tape-recorded and will last about 45-60 minutes each. After the tape-recorded interview, you will be asked to answer four questions. The first question asks whether you have health insurance.

The second question asks about your marital status. The third question asks for your employment. The fourth question asks about the highest level of schooling that you had. For your time in the study, you will receive a $20.00 gift certificate.

Risks:

In this study, you will most likely not have any more risks than you would in a normal day of life. However, it is possible that talking about negative experiences you may have had because of your weight may cause you to become upset. If being in this study causes you distress, Winsome Stephenson will talk with you about finding a counselor. However, Georgia State University does not have funds set aside to pay for such care or to provide you with compensation if you should need care.

Benefits:

Being in this study may not benefit you personally. Overall, we hope to gain information about the experiences that larger African American women have when they use healthcare services. We also hope to determine if these experiences cause the women to delay healthcare for screens that would find breast and cervical cancers. This information may help us to plan interventions that will help larger African American women to seek timely screens for these cancers. We also hope to prevent the many deaths from breast and cervical cancers that are seen in larger women.

Voluntary Participation and Withdrawal:

Participation in this research study is voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may chose not to answer an interview question at any time. Whatever you decide, you will not be penalized in any way for the decision you make.

Confidentiality:

We will keep your records private to the extent allowed by law. We will use a number code or pseudonym rather than your name on all study records. Only Winsome Stephenson and Dr. Moloney will have access to the information you provide. Information may also be shared with those who make sure the study is done correctly (Georgia State University Institutional Board, Mercer University Institutional Review Board, the Office for Human Research protection and/or the Food and Drug Administration [FDA]). The information you give us will be stored in a locked file. We will use a code key to identify which files are yours. This code key will be kept in a separate locked file, away from the data. The code key will be destroyed one year after the study is ended. Someone who does not know your identity will transcribe your

interview tapes. The typed transcripts will have no information that might identify you. The audio-tapes will be stored in a locked file cabinet in the student researcher's home. These tapes will be destroyed one year after the study has ended. Your name and other facts that might point to you will not appear when we present this study or publish its results. The findings will be summarized and published in group form. You will not be identified personally.

Contact Persons:

Call Dr. Margaret Moloney at (404) 413-1170, email mmoloney@gsu.edu or Winsome Stephenson at (678) 468-9556, email wins12345@aol.com, if you have questions about this study. If you have questions or concerns about your rights as a participant in this research study, you may contact Susan Vogtner in the Office of Research Integrity at Georgia State University at 404-413-3513 or svogtner1@gsu.edu or Ms. Ava Chambliss-Richardson in the office of Research Compliance at Mercer University at 478- 301-4101.

Copy of Consent Form to Participant:

We will give you a copy of this consent form to keep.
If you are willing to volunteer for this research and be tape-recorded, please sign below.

☐ I give my consent to participate in this study

☐ I DO NOT give my consent to participate in this study.

Participant's First Name:_____ Last Name:_____ Date:_____

Participant's Signature_____

Please complete your telephone contact information below, so that we can reach you.

_____

Preferred telephone Number (s)

_____ _____

Student Principal Investigator Date

Appendix D

Recruitment Flyer

Appendix D

Georgia State University School of Nursing

The study is conducted by Winsome Stephenson, a student who is working on her PhD. In Nursing

The Experiences of Overweight African American Women as they have Utilized Healthcare Services: The Influence of their Experiences on Utilization of Preventive Healthcare Services

VOLUNTEERS WANTED FOR RESEARCH STUDY

What is this study about?

Hearing the experiences that large sized African American women have with health care services.

Who is eligible?

- African American woman 18 years of age or older who are overweight

What's involved in the study?

- Two interviews that will be tape-recorded
- A $20.00 incentive payment for your time

What are the benefits of joining?

- Help researchers better understand the experiences that larger African American women have when they seek healthcare
- Help to provide good healthcare for larger African American women

Who to contact?

To volunteer or for more information, please contact Winsome Stephenson at (678) 468-9556