Healthcare narratives across the generations and their impact on contemporary healthcare practices of young African American women

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ABSTRACT

African American women are more likely than those in any other ethnic group to die from heart disease, cancer, and stroke and are less likely to seek treatment. The literature suggests that healthcare patterns are passed down through generations and that familial influences have a significant impact on healthcare behaviors, independent of other factors known to influence healthcare access such as poverty. The aim of this exploratory study was to pilot an innovative, multi-modal protocol designed to facilitate a discussion about personal healthcare narratives and the influence of previous generations on health-related attitudes. Methods: convenience sampling recruited seven young African American women, ages twenty three to thirty, who agreed to participate after reviewing the informed consent. The protocol included structured interview questions, an interactive story-board organizing around “circles of influence,” a survey of preventative health practices, and open ended questions. Interviews were transcribed and digital photographs were taken of participant storyboards for later analysis. Findings: The interactive nature of the protocol helped to facilitate detailed discussion and was a relatively easy way to capture data for later analysis. Participants described a wide range of relatives and associates within their circles of influence. An unexpected finding was the impact of having children on current healthcare choices of women in the sample.
HEALTHCARE NARRATIVES ACROSS THE GENERATIONS
AND THEIR IMPACT ON CONTEMPORARY HEALTHCARE PRACTICES
OF YOUNG AFRICAN AMERICAN WOMEN

A project based on an independent investigation
submitted in partial fulfillment of the requirements
for the degree of Master of Social work

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This study searched to expand our knowledge about the influences that shape health care decisions among young African American women (AAW). African American women are more likely than those in any other ethnic group to die from heart disease, cancer, and stroke and are less likely to seek treatment both for these as well as mental health related concerns (Boyd, Chen, & Benton, 2009; National Center for Health Statistics, CDC, 2011). The literature suggests that familial influences may have a significant impact on healthcare behaviors, independent of other factors known to influence healthcare access such as race and poverty. The aim of this exploratory study was to pilot an innovative, multi-modal protocol designed to facilitate a discussion about personal healthcare narratives and the influence of previous generations on health-related attitudes. While there is some research evidence to suggest that healthcare patterns are passed through generations (Davis, Rovi, & Johnson, 2005), there is virtually no research which has explored these influences on the healthcare choices and help-seeking behaviors of African American women (AAW).

Because of the seriousness and extent of race-related health risks associated with African American heritage, it is hoped that the study proposed here will sensitize social workers to these risks, and provide some insight into narrative approaches for exploring and resolving these risks in client-centered work.
CHAPTER II

Literature Review

The literature review is divided into four sections. The first section documents the health outcomes disparities research among African American women and provides a rational for the study. The second section discusses the role of the family in developing and influencing health-related (and other) values. The third section describes the development and function of the African American family. The forth section reviews change theories as a model for conceptualizing what is needed to transform behaviors and ideas.

Current Health Risks among African American Women

There is a substantial public health research literature describing health care outcomes and utilization among African American women. (CDC, 2011; Cole, Stevenson, & Rodgers, 2009; Brown, Namen, Homel, Fraser-White, Clare, & Bowne, 2006). This literature focuses predominantly on health outcomes disparities across ethnic and economic groups, emphasizing that African American women are more likely than those in any other ethnic group to die from the leading causes of death among American women: heart disease, cancer, and stroke (National Center for Health Statistics, CDC, 2011) and are less likely to seek treatment (National Center for Health Statistics, CDC, 2008). AAW also experience depression at higher rates than their Caucasian counterparts and are less likely to use formal mental health resources less than other races (Cole et al., 2009).
Public health-centered research has examined differences in health outcomes for African American women as compared to other races. The National Health Interview Survey (NHIS) is an annual, cross-sectional survey intended to provide nationally representative estimates on a wide range of health status and utilization measures among the nonmilitary, noninstitutionalized population of the United States. Each annual data set can be used to examine the disease burden and access to care that individuals and families are currently experiencing in the United States. Data are collected from household level interviews.

Employing a cross-sectional analysis of participants from the National Health and Nutrition Examination Survey between the years 2001 to 2006, Redmond, Baer, and Hicks, (2011) examined how hypertension and blood pressure affect various races and ethnicities in the United States. They reported that African Americans and Mexican Americans had higher odds of uncontrolled blood pressure compared to white Americans. A recent study making use of the NHIS data examined access to breast imaging services for non-black Hispanic and African American women in Chicago and found that minority women had less access to high quality technologies and specialists than their majority counterparts (Rauscher, Allgood, Whitman, & Conant, 2012). Poor access to screening technology and services are associated with higher rates of morbidity (Vital Signs: Racial Disparities in Breast Cancer Severity — United States, 2005–2009. Weekly, November 16, 2012, 61(45);922-926).

To investigate why breast cancer mortality is higher for African American women than white women, even though there is a lower incidence of breast cancer among AAW, records from the Wisconsin cancer reporting system were compared to the database maintained by the National Center for Health Statistics to view trends of breast cancer mortality from 1995-2006 (Lepeak et al., 2011). The researchers found that, while there was an overall decline in breast
cancer mortality from 1995 to 2006 among all women, mortality rates for African American women remained high as compared with other ethnic groups (Lepeak, et al., 2011). These studies all highlight the prevalence and disparity of health risks for African American women.

An area that has not received much attention relates to health messages that African American women receive from important figures in their lives. Information about the impact of family values, the definition of family within the AA population, understanding the impact of the social climate for this population, and knowing theories of change all support the need for further investigation on the learned health messages for African American women and the relevance for their current health values.

Family Influences

Throughout the course of its development, families instill fundamental and enduring assumptions about the world, passing on values that members carry with them throughout their lives (H. Goldenberg & I. Goldenberg, 2008). Messages regarding adaptability, problem solving, communication, and understanding of roles have been identified as important factors contributing to more positive outcomes for all family members (Dubar et al., 2008). Through the verbal discourse and routines set by those in authority in families, values are formed and learned by the members. Reis (1996) identified the family, in particular parents, as an important place to focus attention when looking at health behaviors and practices of the children. She conducted a descriptive study with 100 low income African American mothers and their children to explore the styles of communication about health and found that although mothers defined health as abstinence from drug use, nutrition, and exercise to their children, they focused primarily on speaking about abstinence from drug use and staying in school as priorities to living healthy
lifestyles (Reis, 1996). This study demonstrates the importance in the type of health messages that children receive from family members.

In a study examining the development of identity formation among African Americans raised in white-dominated neighborhoods, Richards (1997) found that AA families instill pride in their children by teaching values through sharing stories of cultural history, and connecting with other African American families to create community. Families identify practices that are protective for its members. Norms develop as practical ways of being in the world are assimilated by family members. These norms tend to be trusted or more highly valued than those of outside groups or influences.

Davis et al. (2005) found significant positive associations between the current health status of participants and familial health status for African American families. The foundation of many health-related views begins with family messages; the health values, behaviors, and teaching styles of parents shape those of their children (Reis, 1996). Values are learned in childhood and inform behaviors in the future. Davis, et al., (2005) looked at generation health patterns relating to obesity and poor mental health with African American families. The study reported that, for the obese African American women who participated in the study, there were higher anxiety levels, poorer perception of their physical health, and had a family history of obesity psychosocial problems. This study demonstrated patterns in family health behaviors that could continue to influence the next generation.

These health behaviors, like other family messages, are not always intended to become family patterns. Unfortunately the repetition of some behaviors is learned through observation and the routine of the family. In interviews with 39 African American mothers about barriers to getting exercise, the participants reported one challenge comes from their role as caretaker
because their attention is dedicated to caring for their children and takes precedent to their own needs (Young, He, Harris, & Mabry, 2008). In considering the reported results from the Davis et al. group (2005), one can see the potential effects of children observing unintentional unhealthy behaviors from their parents.

The literature suggests that families are an important source of information about health. Families come in many forms and made up of different relationships. The next section discusses the structure of “families” in the African American culture.

**Definitions of Family**

**Function of the African American family.** The function and structure of families has evolved throughout United States history. From its origins as a larger kinship network that helped with farming, to the nuclear family of the 1950s, the purpose of the family has changed as society has modernized. Most simply, a family is a group that functions to meet the collective needs and goals of its members. Families must do this without consistently and systematically preventing members from meeting their individual needs and goals (Kantor & Lehr, 1975). The family is formed in order to raise and nurture younger human beings until they reach maturity while at the same time, educating and protecting its members (McGoldrick & Hardy, 2008). The hope of the family is to strengthen its individual members so that, in turn, the family can be a stronger group. Hines and Boyd-Franklin (1996) describe the African American family with the African philosophy, “we are, therefore I am,” to illustrate the communal minded nature of the African American family. As African Americans have a history of being an oppressed population in the United States, family members turn to one another to instill qualities necessary to survive in a racist society. African American families work hard to create a community, with the goal of creating a pride in their identity as African American (Richards, 1997). Trying to
instill pride in their children’s identity is a helpful coping technique when facing external prejudice and socio-cultural barriers.

African American families are recognized as both a community institution and the predominant instrument of socialization (Tucker & Mitchell-Kernan, 1995). AA families value the art of improvisation; these families work well developing methods to survive and thrive with the help of individuals that they trust (McGoldrick & Hardy, 2008).

**Composition and purpose of the African American family.** In the African American community, extended kin (including uncles, grandparents, cousins, etc), and non-kin persons who have a close relationship with individuals, are treated as family and are relied upon for support (Jarret, Jefferson, & Kelly, 2010). The history of oppression of African American families has led to division of the members through slavery and imprisonment; men were separated from their families, which led to other members and trusted persons joining the family unit to help (McGoldrick & Hardy, 2008). Financial assistance, childcare, protection, and emotional support are all a part of these community relationships (Jarret et al., 2010).

These extended “family” networks provide sources for emotional development. Focus on community involvement and extended family networks instill pride while developing self-esteem for members who may not receive those qualities outside of the community (Richards, 1997). Support from family or community members is extremely important for African American women. While conducting focus groups about health values with 24 African American women in Detroit, participants defined health as being “connected to the world” and as including active participation in ones community (Schulz & Lempert, 2004). From this perspective, involvement with family and extended kin/community “is” health.
Although marriage is an ideal within the African American community, many individuals have children while not married, with many different configurations in partnering and child rearing (McGoldrick & Hardy, 2008). There are many criticisms of the trend within the African American community of female-headed households and absent men (Tucker & Mitchell-Kernan, 1995). These critiques ignore the impact of racism and discrimination in which AA families have lived, such critiques create stress and a negative image of African American families. From another perspective, the difference in division of parental roles in AA families speaks to the coping strategies and survival instincts of the African American family and the strength and flexibility of the members.

Acknowledging the difference in family structures is imperative when attempting to understand the influences on African American women that shape their health values. Hines and Boyd-Franklin (1996) point out the need for those working with families to recognize that the structure of the family is not as important as a focus on the functioning of the family.

Knowing who is identified as family and community will be crucial in exploring the learned health behaviors of African American women.

Social-Political Environment

When discussing the role of the family in the creation of values, it is important to consider the events or context that create the need for those values (H. Goldenberg & I. Goldenberg, 2008). Although the context of family is important for understanding the values and dynamics that play out with the individual, cultural influences cannot be underestimated. Although individuals are responsible for instituting and maintaining the lifestyle changes needed to reduce health risks, individual behavior change is determined, largely, by social-environmental contexts such as community norms, cultural practices, and discrimination issues.
(Bhattacharya, 2012). These factors set the stage for how values are instilled based on the protective needs of the family members.

Reality for families are not objective, but are related to the subjective experience based on their social constructions and can be carried on for generations. All subjective truths can become blinders or limitations by preventing family members from noticing other behavioral options (H. Goldenberg & I. Goldenberg, 2008). Systemic factors such as socioeconomic status, race, and one’s role within the family are likely to be prioritized over efforts directed toward promoting better health, which may not be reinforced as a priority (Pekmezi, Barbera, Bodenlos, Jones, & Brantley, 2009; Young, et al., 2008). Schulz and Lambert (2004) conducted focus groups with low-income African American women in Detroit to discuss their perceptions of health in their communities. One major finding was that the women reported that segregation of neighborhoods due to racism and classism created a disparity in health services and resources for their community. In a home intervention with 214 low-income African American women with chronic illness, Pekmezi, et al. (2009) found that greater success for this program was associated with support from attention multiple levels of various systems such as policy and community and health organizations. Young, et al. (2008) found that, in addition to the burden of family roles and responsibilities creating barriers to maintaining physical health for low-income African American women, participants reported that the lack of neighborhood health facilities were also major access barriers. The findings from these studies demonstrate the effects of the classism and sexism on health disparities for African American women.

In a quantitative longitudinal study with children ages newborn to eight years, Strauss and Knight (1999) found that children from all races with obese mothers, lower family incomes, and lower cognitive stimulation were linked to having a significantly increased risk of being
obese themselves. For African American children specifically, obesity was linked to low income and lower levels of cognitive stimulation.

In their research on African American women’s views about mental illness and stigma, Ward and Heidrich (2009) state: “Negative sociopolitical experiences including racism, discrimination, and sexism put African American women at a high risk for low income jobs, multiple role strain, and health problems, all of which are associated with the onset of mental illness” (p.480). Greater support from systemic organizations will increase a healthier environment and addressing macro-level issues such as racial segregation and imbalance in funding, allow for awareness about health.

**African American perception of the Mental Health system.** Mental health treatment is a controversial subject for many cultures. Within the African American community, there is skepticism about institutionalized mental health treatment. A focus groups with 30 low income African American women with depression found that women had a mistrust of the health care system as racist and ‘white.” Participants identified feeling more comfortable with service providers of the same race (Nicolaidis et al., 2010). Ward and Heidrich (2009) found that African American women understood the value of mental health treatment, but preferred to use religious communities and prayer to cope, and that all age groups denied perceiving stigma about mental health treatment, although older women were more likely to endorse mental health treatment than other age groups. These studies suggest a preference for seeking support and care within the community through natural supports rather than from external organizations and illustrate the impact of community as family on shaping health attitudes among AAW, particularly with regard to mental health care.
Change Theories

Any maladaptive behavior needs to be changed for the better functioning of the individual and community. To make any change, one has to recognize the benefits that will occur as a result. This is especially important when considering the source of those behaviors and the attachment to that behavior. Culturally relevant approaches for the African American population will increase success when trying to create health changes (Pekmezi et al., 2009).

Stages of Change. Lifestyle changes take time to happen, they do not occur instantly. Prochaska and DiClemente (1986) introduced the stages of change framework that has influenced theoretical model of behavioral change for decades. This model is identified as the dominant theory used to promote health change and incorporates concepts needed to assess change: the decisional balance scale (pros and cons of behavior change), strength and weakness principle, processes of change and self efficacy (Kelly, 2005). Each component influences how one thinks about other behaviors as they relate to the change they want to make.

Knowledge of risks alone is not enough to change behavior; other factors need to be taken into consideration for change to occur (Brown et al., 2006). Unhealthy behavior patterns are not isolated incidents, but coincide with other unhealthy patterns; by the same token, one behavioral health change usually influences others (Kelly, 2005). Behavioral change requires thinking about, or contemplating, one’s health.

Much of the literature on health dynamics with African American women has investigated aspects of change (Pickard, Inoue, Chadiha, & Johnson, 2011; Brown, et al., 2006). Pickard, et al. (2011) studied the motivations behind help-seeking behaviors of African
American parents (caretakers). They found that the level of stress, age, and asking members of a trusted religious community and family members were the only indicators associated with the likelihood of asking for help. Brown, et al. (2006), conducted surveys with African American and African Caribbean women in beauty shops in Brooklyn, NY to measure their level of awareness about health risks and prevention strategies. Findings from this study report that although the women were aware of health risks associated with their population, many still engaged in high-risk behaviors (Brown, et al., 2006).

Family Systems Theory

In attempting to understand the connection between the transmission of family values and the relationships between family members, in the 1950s, Murray Bowen, researched how schizophrenia impacted a mother child relationship (Bowen, 1990). From this research, Bowen developed what is now referred to as Bowen’s family systems theory which says that the family is an emotional unit that is best understood when looking with a multigenerational lens (Bowen, 1990). Of Bowen’s key concepts in the family system’s theory (FST), one most important for this proposed study describes a multigenerational transmission process in which family dysfunctional patterns resulting from ‘chronic anxiety’ are transmitted over several generations. As described by H. Goldenberg and I. Goldenberg (2008), the amount of differentiation (or balancing knowledge with felt experience) a family member develops will dictate the likelihood of changing those dysfunctional habits. Bowen (1990) states:

When one member of a family can calmly state his own convictions and beliefs, and take action on his convictions without criticism of the beliefs of others and without becoming involved in emotional debate, than other family members
will start the same process of becoming more sure of self and more accepting of others (p.252).

This lens, when interpreted with consideration of what it means to be an individual within the family in various cultures, is a helpful construct when considering the development of the health values for the AA community. The model predicts that greater levels of differentiation predict greater psychological adjustment and social problem solving skills. It also associates stronger relationships with families with a greater feeling of belonging to ones ethnic group (Skowron, Webster, & Azen, 2004). Differentiation, as a strong correlate to changing family norms, is important when looking at negative health–related patterns within African American families.

Summary

Although there has been research about current values and behaviors relating to physical and mental health outcomes for African American women, there is little exploration of how intergenerational family and community messages have influenced those behaviors and beliefs. Understanding the role of family in instilling health-related values, considering the historical and practical role of the family in the African American community, and recognizing the impact of the social environment in which African American women live, provides a strong background for this study.
CHAPTER 3

Methodology

Overview

The aim of this small exploratory study was twofold: 1) to test an interview protocol designed to facilitate a discussion with African American women about their own personal healthcare narratives, and 2) to explore the influence of previous generations on the health-related attitudes and practices of young African American women. The study interviewed seven young African American women, asking about their recollections of familial and community health-related attitudes and behaviors. These reports were compared with the contemporary healthcare behaviors of the same women in order to explore the possible impact of these trans-generational and trans-community influences on contemporary health practices.

Research Design

This qualitative study employed an exploratory design with case study methods. Qualitative interview strategies allow for a narrative approach in collecting data. One of the advantages of this approach is the close collaboration between the researcher and the participant, while enabling participants to tell their stories (Baxter & Jack, 2008).

Sample

A non-probability convenience sample was used to recruit 7 young African American women from a pool of participants a metropolitan YMCA that hosted the project. Over the course of a month and a half that the study was open, eleven women expressed their interest in
participating. Two were found to be ineligible due to not self-identifying as African American. Two other women were interested but were unable to meet due to conflict in scheduling.

**Inclusion criteria.** Participants had to be 19 to 30 years of age, female, and identify as experienced in the world as African American, and be currently enrolled as a member or staff of the host YMCA.

**Exclusion criteria.** Women who otherwise meet enrollment criteria were excluded if they did not agree to participate in the study as indicated by signing the Informed Consent, or if they were unable to participate due to inability to comprehend the study. Participants were also excluded if there were no securities in place for basic needs, such as housing and food.

**Sample size.** We hoped to recruit 12 participants for the study. As described above, 7 women completed the interviews.

**Recruitment Procedures**

Once receiving a signed letter of agreement from the host Y, and after HSR approval from Smith College was received, the study was advertised through word of mouth and through posting a recruitment flyer (Appendix A) throughout the host “Y.” The flyer described enrollment criteria and the nature of the study, and provided contact information for study enrollment. The researcher also attended a family event hosted by the host program as outreach for the study. Participants interviewed before April 30, 2013 were included in the study.

Potential participants who contacted the investigator were provided with information about the study and had an opportunity to have questions answered. They were asked about their age, if they identify as an African American woman, if they have supports in place for housing and food, and if they were involved with the YMCA (inclusion criteria). There were Applicants who did not meet inclusion criteria. They were informed of this and were thanked for their time.
and interest in the study. Applicants who met enrollment criteria were invited to participate in the study. When they expressed interest, a mutually agreeable time was identified to meet within the upcoming week, and contact information (phone number or email) was exchanged. Applicants were also invited to tell other African American women about the study. Participants were contacted one day prior to the interview to confirm the meeting time and place.

**The nature of participation:** Participants arrived at a pre-arranged time; the interview was conducted in confidential space provided by the host “Y.” The interview room was easily accessible to participants and had a door that closed. The first activity was a review of the informed consent, including an opportunity to have any questions about the research addressed. If the woman did not want to enroll in the study after reviewing the informed consent, she was thanked for her time and the interview ended. Participants were provided with a copy of the informed consent that they could keep. All of the enrollees completed the interview after signing the informed consent.

The interview protocol designed for this study had three sections. Interviews took about 30 minutes to complete, on average. The first section collected information about the woman’s individual characteristics such as age and type of health insurance. This information was collected in order to later be able to stratify the sample by subject characteristics. The second section uses an interactive display, a 3’ x 3’ poster as depicted in the photo on the right. The “circles” board will be introduced and explained.
A copy of the interview guide can be found in Appendix D. Participants were asked to identify whom they considered members of their family and community, and to place these significant relationships in one of three possible “circles” or classifications: family, core community, and casual community. The interview included materials to help organize and prompt participants.

A “circles board” was present during the interview and illustrated three possible places where important relationships could be classified. These classifications were family (inner most circle), core community (middle layer), and casual community (outer circle). Narrative approaches were selected because this approach encourages participants to reflect in some depth about the questions and describe their views, while allowing the researcher to better understand participant’s actions (Lather, 1992). A short structured questionnaire was also employed to capture information about the health practices of the participants.

Women were asked to write the first name of members of their family, core community, and casual community on a piece of sticky paper, and to place the name within the ring that best captured the nature of their relationship (family, core community, or casual community). After naming members and placing them in the appropriate circle of reference, the women were asked how the community member was related to her. For example, “Mary” may be placed in the “core community” circle and be identified as a cousin. “Genella” may be placed in the “family” circle and identified as a sister. “Monique” may be placed in the family circle and identified as a grandmother or church member. (These names are used for illustration and were not names collected during the study). After the woman finished completing her “circles,” a photograph of the board was taken for later analysis. Care was taken to be sure that participants did not appear in the photo.
Next, participants were asked to inspect the “circles” board they had just created and select three people from among those listed whom they felt had the most impact or influence on their health beliefs and practices. She was then asked to describe the influence that each of the three people has had. This section of the interview, lasting about 10 minutes, was digitally recorded for later analysis. The third part of the interview gathered information about each participant’s health beliefs and self-reported health care utilization. Responses were recorded by the interviewer on a paper form prepared for the discussion.

**Ethics and Safe guards**

**Risks of participation.** The nature of the interview was to facilitate a discussion about the woman’s personal healthcare narrative, with particular interest in how the values and attitudes passed down to her from previous generations may affect her current healthcare choices. This involved answering questions about personal health practices. Given this context, there was a risk that participation could elicit emotional discomfort or stress. A printed list of accessible (free) health and mental health resources was provided to each participant as part of the informed consent process should they be needed.

Since participants may be introduced to the study by staff at the “Y, it is possible that a participant could feel compelled to participate in the study. To address this possibility, care was taken to assure participants of the voluntary and anonymous nature of participation, specifically indicating in the informed consent that their program staff would not know if they choose to participate or not. “Y” staff were also be asked to provide a copy of the study flyer to interested women rather than being more active in recruitment by acting as an intermediary for the study.

Finally, all participants received as an attachment to the informed consent a list of referral sources that anyone may access (i.e., resources that are not restricted by payment or insurance).
A copy of the informed consent document including the list of referral sources appears Appendix C.

**Benefits of participation.** Participants did not receive any tangible benefits, including money or goods, for participating in the study. Participants may have benefited by reflecting on the influences that inform their personal healthcare narratives. Participants may have gained satisfaction in the knowledge that the data collected in this study may be used to justify further research into this important topic.

**Voluntary nature of participation.** Participation in the study was entirely voluntary. Participants could end their participation at any time. They could choose not to agree to the letter of consent, or, once the study began, could skip questions. They could ask to withdraw from the study entirely if the request was received on or before April 30, 2013, in which case their data would not be included. No such requests were received. Interviews lasted, on average, about 30 minutes, including the informed consent procedures.

**Precautions taken to safeguard confidential and identifiable Information.** The research design and methods were designed to protect to the greatest extent possible the identity of participants. Procedures insured that the identity of participants would remain anonymous and that responses to questions would be treated confidentially. The following procedures were followed. Each participant was assigned a unique identifier. All demographic and qualitative data were coded and organized using the unique identifier. Participants were asked not to include identifying information in their verbal responses to open-ended questions. Qualitative data was transcribed and carefully checked. No personally identifying information was revealed on taped portions of the interview.
Interview tool. The interview guide was a paper and pencil form. Some information the woman provided was written on the form by the interviewer. The form was coded with the subject’s unique ID. Forms were kept in a locked file cabinet in the researcher’s control.

Photographs. A digital photograph was taken of the “circles poster” for later analysis. The photographs were stored electronically on password-protected media in the researchers control. The file name for each photo contained only the unique ID assigned to the participant. Digital recordings: a 10 minute segment of the interview was digitally recorded. No personally identifying information, if disclosed, was transcribed. Digital recordings were stored electronically on the researcher’s personal password protected computer, in a file that also requires a password to access.

Published reports: Date were aggregated for this report.. Care was taken to disguise any possibly identifying information, including the host site of the study.

Data retention and destruction. All electronic and paper data will be stored for three years in password protected folders on a personal password protected desktop computer accessible only to the researcher. Data will be destroyed after three years in accordance with Federal guidelines. The computer is equipped with the latest antivirus and antispyware software that is available. Physical documents are stored in secure and locked file cabinet in the researcher’s possession and will be kept for the minimum three years as required by Federal guidelines and then destroyed. If the data are needed for a longer period of time, they will be kept securely as described above and destroyed when no longer needed.

Human Subjects Review Board

The study proposal was submitted to the Human Subject Review Board (HSRB) at Smith College. Data collection began after receipt of HSRB approval, assuring that all materials met
Federal and college standards for protection of human subjects. A copy of the HSRB’s approval letter may be found in Appendix E.
**Data Collection**

The data collection process involved an in person interview. The details about study participation are described in some detail in the section Nature of Participation. The interview protocol, designed for this study, had 3 sections. The first section collected information on the participant’s individual characteristics such as age and type of health insurance. The second section used an interactive display to explore participants’ social and familial networks, and asked each woman to describe the health beliefs and related messages passed on from these connections. The third section captured self-reported health care utilization and unmet needs for healthcare.

**Informed consent procedures.** Ensuring that individuals are fully informed about the research study and their participation in it is a critical component of the research design. Potential participants who agreed to meet were with the researcher were handed a copy of the informed consent letter (Appendix C) at the beginning of the interview and asked to read the information or, if they preferred, the document was read to them. Time was allowed to ask questions about the study or informed consent.

Once participants reviewed the informed consent letter they indicated their consent by signing the form and the interview began. A copy of the consent was given to the participants to keep for her records. The informed consent was labeled with the unique ID of the participant. Once signed, the informed consent was dissociated from other study materials and kept in a locked file cabinet under the researcher’s control. Other than the participant’s signature, no other personal identifying information (PII) appeared on the Informed Consent.

**Strengths:** A primary aim of the study was to develop and pilot a methodology for looking at this complex set of issues. In this regard, the study was innovative and addressed an
area not previously explored. The methodology piloted in the study was based on a thorough review of relevant literature. The choice of this design supported the project goals of gathering information about the cross-generational messages that AAW hear, and how or if those messages color the woman’s perceptions of what constitutes “good health” and “good health care.”

**Limitations:** The primary limitation of this study is the small response size, which prohibited in depth interrogation of the data. The five weeks allotted to collect data was insufficient for reaching a meaning sample size for this exploratory methodology.

**Methodological bias.** The study’s methodology has bias. First, selection bias was generated by the fact that the sample for this study was relatively small in size and nonrandomized. Further, only those who could read and write in English and who were members of the host “Y” could participate.

**Other aspects of researcher’s identify:** The researcher is an “insider researcher.” The researcher was aware that her experience may bias her approach to this study and has attempted to mitigate this bias through the methods selected for the study. Literature on the process of research has identified the insider researcher, someone who conducts research with communities of which one identifies as a member (Kanuha, 2000). In this case, the researcher is an African American woman who comes from a low-income household. Considering this identity, the researcher was an insider researcher in terms of the conduct of this study. The researcher also recognizes that her experience in no way renders her an expert in this area. Rather, as Hayano notes, “an insider’s position is not necessarily an unchallengeable ‘true’ picture; it represents one possible perspective” (as cited in Kanuha, 2000, p. 443). The researcher was aware of the possibility of neglecting to ask questions about certain aspects of the participants’ experiences out of bias caused by her own personal experiences and identity.
Data Analysis

Once the data were all transcribed, themes were identified and compared across participants. Responses were examined to explore: (a) who family is to the participants, (b) patterns in family healthcare values and utilization, (c) the connection of those patterns to the health-related values of participants, and (d) health-resource utilization (actions) of participants. The information on the woman’s individual characteristics, health beliefs, social supports, self-reported health care utilization, unmet needs for health care, and self-reported barriers to accessing health care provide a clear picture of the role of health in their lives.

The next section presents the study findings.
CHAPTER IV

Findings

This was an exploratory study using qualitative methods design. The aim of this small project was to pilot an innovative, multi-modal protocol designed to facilitate a discussion about personal healthcare narratives and the influence of previous generations on health-related attitudes. The goal was to explore the influence of previous generations on the health-related attitudes and practices of young African American women. The study interviewed seven young African American women, asking about their recollections of familial and community health-related attitudes and behaviors. Their reports were compared with the contemporary healthcare behaviors of the same women in order to explore the possible impact of these trans-generational and trans-community influences on contemporary health practices.

This chapter contains a demographic description of the sample and summaries of the qualitative data, including a description of relationships participants identified as family, detail about participants and their influential person’s health practices, and patterns in participants responses of what it means to be healthy. Due to the small sample size, findings are not reliable and should not be read a such. However, some observations and inferences can be made for further exploration, as will be discussed in Chapter V.

Demographic Information
Demographic information collected included: age, relationship status, primary language, city of birth, and number of children. Women enrolled in the study ranged in age from 23 to 30 years of age.

Table 1

*Relationship status and number of children (N=7)*

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>3</td>
<td>42.8</td>
</tr>
<tr>
<td>Married</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td>Committed relationship</td>
<td>3</td>
<td>42.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>7</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Number of Children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>42.8</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>28.5</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>7</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 2

*Employment status and education level (N=7)*

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>2</td>
<td>28.5</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
<td>57.1</td>
</tr>
<tr>
<td>Student</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>7</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some High School</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>2</td>
<td>28.5</td>
</tr>
<tr>
<td>Some College</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td>Associates Degree</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>7</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Table 3

Place of Birth

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of Birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boston</td>
<td>3</td>
<td>42.8</td>
</tr>
<tr>
<td>New York</td>
<td>3</td>
<td>42.8</td>
</tr>
<tr>
<td>Haiti</td>
<td>1</td>
<td>14.2</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>100.0</td>
</tr>
</tbody>
</table>

This is a small, relatively homogenous sample. All participants were women, English speaking, and identified as African American. All but one participant had children. And, participants were close in age, with the range being from 23 to 30 years. Within the small sample, there was some diversity represented. The majority of the participants were not born in the Boston area, and there was a wide range in education levels, with two-thirds of the participants having attended some college.

Circles of Influence

Please refer to the methods section for a detail description of how the interviews were conducted, and to Appendix D for a copy of the interview guide. Findings demonstrate that, as anticipated, there were meaningful differences in the ways that participants categorized people whom they considered family, their core community, and their casual community.
Family: Women were read the following instructions: Please tell me the first name and relationships of people whom you consider to be “family.” The prompt used was: Families come in many forms. Sometimes those whom we call ‘family’ are related to us. Sometimes people we consider ‘family’ are not related. This could be relatives or neighbors, co-workers, boss or employees, pastor or church member, teachers, other students, community members, whoever you consider family. These may be people that you call in times of crisis, or to share exciting news. These may be people you trust most. They are whomever you call “family.”
Table 4

*Family: Types of relationships, grouped by relationship type (N=7).*

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Frequency</th>
<th>Within group % of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First degree relatives</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>10</td>
<td>18.9</td>
</tr>
<tr>
<td>Mother</td>
<td>5</td>
<td>9.4</td>
</tr>
<tr>
<td>Brother</td>
<td>5</td>
<td>9.4</td>
</tr>
<tr>
<td>Child(ren’s) father</td>
<td>5</td>
<td>9.4</td>
</tr>
<tr>
<td>Sister</td>
<td>4</td>
<td>7.5</td>
</tr>
<tr>
<td>Dad</td>
<td>3</td>
<td>5.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>32</td>
<td>60.0</td>
</tr>
<tr>
<td><strong>2nd Degree relatives</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aunt</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>Cousin</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>5</td>
<td>9.4</td>
</tr>
<tr>
<td><strong>Unrelated</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Best friend</td>
<td>6</td>
<td>11.3</td>
</tr>
<tr>
<td>Friend</td>
<td>6</td>
<td>11.3</td>
</tr>
<tr>
<td>Best friend’s mother</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Pastor</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Church member</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Coworker</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>16</td>
<td>30.2</td>
</tr>
</tbody>
</table>

Table 4 describes the type of relationships identified in this category and the number of people who identified this relationship. 70% of those classified as “family” members were made up of first and second degree relatives. 30% of designees were unrelated.

As participants gave the name of individuals they consider family, they automatically described the relationships for the interviewer, without prompt. While discussing their family members, all of the women also talked about trust and how each individual they chose had proven that they could be trusted. Participants talked about devastating times in their lives when
a family member provided guidance or helped them through the situation. For those participants who were also parents, family members were described as the people who provided support and education about parenting. All participants who were parents listed their children in this section.

**Core community.** The instructions given for this section was: Please identify people that you would place in your core community. The prompt used was: Your core community may be people that you feel close to or whom you rely on. This could be relatives or neighbors,

Table 5

*Core Community: Types of relationships, grouped by relationship type (N=7)*

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Frequency</th>
<th>Within group % of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>First degree relatives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>1</td>
<td>9.0</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>9.0</td>
</tr>
<tr>
<td>Grandmother</td>
<td>5</td>
<td>45.4</td>
</tr>
<tr>
<td>Step-mother</td>
<td>3</td>
<td>27.2</td>
</tr>
<tr>
<td>Aunt</td>
<td>1</td>
<td>9.0</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>100.0</td>
</tr>
<tr>
<td>Friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Best friend</td>
<td>1</td>
<td>3.8</td>
</tr>
<tr>
<td>Cousin</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>9.4</td>
</tr>
<tr>
<td>Unrelated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Best friend</td>
<td>6</td>
<td>11.3</td>
</tr>
<tr>
<td>Friend</td>
<td>10</td>
<td>11.3</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Organizations / Work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coworkers</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>Church member</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>Neighbors</td>
<td>4</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>30.2</td>
</tr>
</tbody>
</table>

coworkers, boss-employees, pastor/ church members, teachers/ other students, community members, whomever you consider in your core community. These may be people whom you
have open communication with, you just may not speak to them as often as you’d like or they are not the first to know what is going on with you (Appendix D). The following describes the type of relationships identified in this category and the number of these relationships that were included:

Of the total of 47 people mentioned by the 7 women, 23% of core community (n=11) members were related family members; only 8.5% (n=4) were “friends.” Two thirds (n=32) of members in this category were unrelated friends or co-workers, church members, or neighbors.

In the core community, participants described individuals whom they see as role models. Some are deceased or live far away. Some participants described current and historical areas of conflict with some individuals that they listed in this circle. There were also some childhood friendships that were once very important to the participants and were no longer quite as close. In this section, some of the participants listed other relationships they had made within the YMCA. Overall, Participants described feeling respect and sense of devotion, in this section.

The definition of family and core community are consistent with the literature which suggest that “family” is an inclusive term of people who can be helpful to the family unit and promote its survival, regardless of actual relationship “by blood.”

Casual Community

The question posed to participants for this section included: Please identify people that you would consider your core community. The prompt was: Your core community may be people that you feel close to or whom you rely on. This could be relatives or neighbors, co-workers, boss/employees, pastor/church members, teachers/students, community members; whomever you consider in your core community. These may be people whom you have open
communication with, you just may not get to speak with them as often as you’d like or they are not the first to know what is going on with you (appendix D).

Table 6

*Casual Community: Types of relationships, grouped by relationship type (N=7)*

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Frequency</th>
<th>Within group % of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First degree relatives</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cousin</td>
<td>4</td>
<td>28.5</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
<td>14.2</td>
</tr>
<tr>
<td>Sister</td>
<td>2</td>
<td>14.2</td>
</tr>
<tr>
<td>Adoptive parents</td>
<td>2</td>
<td>14.2</td>
</tr>
<tr>
<td>Brother</td>
<td>1</td>
<td>7.1</td>
</tr>
<tr>
<td>Husband</td>
<td>1</td>
<td>7.1</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1</td>
<td>7.1</td>
</tr>
<tr>
<td>Uncles</td>
<td>1</td>
<td>7.1</td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Friends</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>God parents</td>
<td>2</td>
<td>18.1</td>
</tr>
<tr>
<td>Friend</td>
<td>9</td>
<td>81.2</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Unrelated</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighbor</td>
<td>2</td>
<td>22.2</td>
</tr>
<tr>
<td>Co-worker</td>
<td>2</td>
<td>22.2</td>
</tr>
<tr>
<td>Teacher</td>
<td>2</td>
<td>22.2</td>
</tr>
<tr>
<td>Service providers</td>
<td>1</td>
<td>11.1</td>
</tr>
<tr>
<td>Networking people</td>
<td>1</td>
<td>11.1</td>
</tr>
<tr>
<td>Church member</td>
<td>1</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>100.0</td>
</tr>
</tbody>
</table>

People had the most difficulty identifying who they would place in their casual community. When participants described these relationships, they often identified that these people were important to them, even out of obligation, but they did not speak very often. Some people identified longstanding conflict with these individuals.
Health Messages and Behaviors of Influential Members

In this portion of the interview, participants were asked to identify at least three individuals who impacted the way they view health. One participant wanted to add two more individuals.

Table 7

*Most influential relationships shaping health-related values and behaviors of subjects*

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Frequency</th>
<th>Within group % of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>From the Family Circle (n=15)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>4</td>
<td>26.6</td>
</tr>
<tr>
<td>Sister</td>
<td>3</td>
<td>20.0</td>
</tr>
<tr>
<td>Best Friend</td>
<td>2</td>
<td>13.3</td>
</tr>
<tr>
<td>Brother</td>
<td>1</td>
<td>7.6</td>
</tr>
<tr>
<td>Daughter</td>
<td>1</td>
<td>7.6</td>
</tr>
<tr>
<td>Son</td>
<td>1</td>
<td>7.6</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>7.6</td>
</tr>
<tr>
<td>Best Friend’s Mom</td>
<td>1</td>
<td>7.6</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
<td>7.6</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Core Community Circle</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandmother</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Mother</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Casual Community Circle</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Husband</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Brother</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The majority of the relationships chosen were from the family category. This means that the participants mostly identified family members as most influential in how they think about
health. When identifying why these individuals were chosen as influential in how participants think about health, participants provided reports of both negative and negative conversations and behaviors.

Themes in the kinds of messages were separated into behaviors and verbal messages. The verbal messages were reported more from female peers and mothers. In two instances, an older male brother was reported as providing verbal messages about health, both positive. Themes from the positive messages include: self care, stress relief, preventive care, safer sex practices, STDs, family history of illness, healthy eating and dieting, prenatal care and children health.

Participants identified both positive and negative behaviors that were influential to their own health views. When participants identified a positive behavior, there was a connection to parenting in some way or often connected to a change in lifestyle that they found inspiring. Attributes that participants described for the positive behaviors included: being disciplined and a commitment to living a healthy lifestyle, healthy cooking and eating, and observing how one cared for their children. These positive behaviors were usually conducted by women with the exception of one participant’s brother who is a doctor and a father who has improved in his alcohol consumption and smoking. Any of the participant’s children that they identified in this section were connected to a positive behavior. This included how the participant learned about having a healthier lifestyle for their children, attending more doctor appointments, and health issues with children that the mothers have learned more about preventing.

Negative behaviors were told out of concern and worry for the individuals participants described. The negative behaviors identified were drug and alcohol consumption, negative relationships with partners, diseases and illness, unhealthy eating, and not going to the doctor for preventive care.
There was a strong relationship with age and negative behaviors, grandmothers were associated with negative behaviors (all responses were about not caring for their own health and having illnesses), and the children were associated with positive health behaviors. In considering patterns of gender, women were more associated with positive behaviors and men with negative.

Figure 2
Types of health-related messages and behaviors reported, by gender of network member

An interesting finding is that although there were a lower number of negative verbal messages from men, there were no negative verbal messages from women reported. The meaning is that the participants were only struck by positive messages received from the women that were influential to them, along with the positive and negative behaviors. It is also noticeable that women were reported more as being influential in how the participants think about health than the men in their lives. This is demonstrated in the frequency of relationships with women given compared to the lower amount of relationships with men that were discussed.
It is interesting that the most influential relationships for thinking about health came from peer-aged individuals. Because these relationships were reported more, there was a wider range of experiences for positive and negative behaviors and messages. For example, one participant said that when around her best friend she drinks. The participant described that at first it was casual, but that her best friend’s boyfriend was murdered, leaving her as a single parent. The drinking happened more as she became more depressed and thus when the participant was around her, she also drank more. The participant identified that this was a bad behavior and
something she wanted to change for herself and her friend. There were also positive reports of peer/ same generation aged influence about health. A common report was about pregnancy. Women spoke about friends or sibling who were pregnant before them and taught them about how to care for themselves while pregnant. They also reported observing and practicing how to care for children through those experiences.

Identifying individuals who have influenced their own views on health led the participants to describe their lives in fuller detail. All women provided the reasoning behind the behaviors of their loved. Reasons for negative behaviors were related to income and neighborhood environment. Coping with violence and death in the family and poverty were frequently mentioned when describing drug and alcohol use. Communication with other loved ones was described as helpful when talking about when a loved one made a positive change in their health. For example,

When one participant described her mother’s illnesses, she said, “she never went to the doctor, and she seemed fine, you know, then she got bronchitis, then pneumonia, then asthma, then diabetes, and now she eats better and goes to the doctor, but we all help. We all watch her and help her prepare meals and make sure she sticks to her appointments. Like we gotta make sure that we are ok” (participant interview, 2013).

Importantly, for both women who mentioned their children as individuals who have taught them about health, the message was always positive, and both women said that they want to care for themselves and do everything to make sure their children are healthy. One woman spoke about her son who had a severe case of asthma since birth. This woman described being
more aware of what can bring on an attack, and reported having all of her children attending regular appointments and eating healthy. She has done a lot of research about ways to reduce attacks, and has even began practicing similar strategies as she too had been diagnosed with asthma as a child. This participant identified going through this experience with her son as the reason she changed her own health behaviors.

**Recommended Health Care**

This part of the interview inquired about important others whom participants identified as influential in her understanding of health-related practices. Figure 4 graphs responses, with particular reference to whether or not the influential person was known to have “good” health-related practices as evidenced by any of the following: check up with a doctor in the last 3 years other than when sick, self-breast exam (women), yearly pelvic exams and pap smears (women), discussed HPV virus with healthcare provider, spoken with a doctor about HIV/STD testing, “safer sex” practices, or been screened for glaucoma.
Table 8.

The preventive care practices of participants and influential relationships.

<table>
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<th>Preventive Health Practice</th>
<th>Performed</th>
<th>Participant</th>
<th>Rel-1</th>
<th>Rel-2</th>
<th>Rel-3</th>
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<td>Had check up with doctor in last 3 year for reasons other than illness</td>
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<td>57%</td>
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<tr>
<td>So self breast exam (women only)</td>
<td>Yes</td>
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<td>4</td>
<td>3</td>
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<td>1</td>
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<td>43%</td>
<td>57%</td>
<td>100%</td>
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<tr>
<td>Yearly pelvic exams/ pap smears (women only)</td>
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<tr>
<td>Talked with health care provider about HPV virus</td>
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<td>Talked with health care provider about HIV/STD testing</td>
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<td>86%</td>
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<td>100%</td>
<td>100%</td>
<td></td>
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<tr>
<td>Talked with health care provider about safer sex practices</td>
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<td>6</td>
<td>5</td>
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<td>86%</td>
<td>71%</td>
<td>57%</td>
<td>100%</td>
<td>100%</td>
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<tr>
<td>Been to an eye doctor and tested for glaucoma</td>
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<td>2</td>
<td>3</td>
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</table>

There results from the survey indicate that a majority of the women were engaging in preventive care behaviors (participant). The one practice that many women were not doing was being tested for glaucoma. There was not a noticeable pattern about preventative care practices of the relationships. Due to the range in ages and gender, there were questions that were not
applicable to certain individuals, or depending on the type of relationship (family, core, casual community), the participants did not know the answers.

**Mental Health**

The women were asked open ended questions about mental health messages they received from their circles. The first question asked to participants was: What have the people in your circle suggested that you do when you feel sad? Responses from participants were: to talk to others about feelings, pray, drink, go for walks, and not talk about their feelings at all.

The second question asked was: Have you gotten any advice about who you might talk to about these feelings? Responses from participants were: to talk to various individuals listed in their circles; God and religious figures. One woman said a therapist, and one person said that they were told to hold their feelings in.

The third question was, “how do members of your circle view professional mental health counseling?” All but two people said that people in their circles were against professional mental health counseling. One woman was herself against it, and three women disclosed that they are in professional counseling. One participant’s father is a pastor and a professional counselor to his congregation and also supports going to outside professionals for counseling. The next question asked “what have been some of the ways that people in your circle have said or shown you about how to handle stress?” The participants identified both positive and negative ways of coping with stress. Responses were: walking, letting others watch their children, sleeping, praying, shopping, drinking, talking to others, and one person mentioned arguing with those who are causing stress.
What is a Healthy Individual?

This was the final session of the interview, ending with two questions. The first asked participants about the qualities they feel make a healthy individual. The women provided various answers. Themes from their responses covered five areas: appearance, emotional health, healthy relationships, physical care, and eating well.

Appearance. Answers participants provided in this category included discussing a ‘healthy’ weight, having “good hair,” “good skin,” and eye color.

Emotional health. Qualities such as happiness, joy, resilience, contentment, stable, security, independence, self-reflection, insight, self-awareness, self love.

Healthy relationships. These included surrounding oneself with positive people, direct communication, and secure attachment.

Physical care. Many participants listed walking, going to the doctors, good hygiene, not smoking, no diseases, exercising, and getting enough sleep.

Eating well. Participants reported not eating junk food, eating fruits and vegetables, drinking lots of water, not doing drugs or drinking often, low intake of carbohydrates, and not eating saturated fats.

Participant’s view of her own health. Participants were asked the question: do you consider yourself a healthy individual?
The majority of women said they felt they were unhealthy. Women who did identify as healthy described themselves as “mostly healthy.” All women said that they were active by nature as they live in an urban area and do a lot of walking, but wished that they could exercise more and eat healthier. Only one woman said that she felt that she ate healthy and identified as eating vegan, the other six women said that they try to eat healthy, but found themselves eating whatever is convenient to them.

**Summary**

The data collected from the interviews suggest a connection between the health messages and behaviors that young African American women received from their loved ones and their own health practices. The data also supports findings from the literature which suggest that the definition of family, at least in this small, non-representative sample, extends to community members. The data also suggest that, although women are aware of specific health risks, they continue to participate in non-preferred ways (for example, eating poorly and not getting enough sleep).
CHAPTER IV

Discussion

African American women are more likely than those in any other ethnic group to die from heart disease, cancer, and stroke and are less likely to seek treatment. The literature suggests that healthcare patterns are passed down through generations and that familial influences have a significant impact on healthcare behavior, independent of other factors known to influence healthcare access such as poverty. The aim of this exploratory project was to pilot an innovative, multi-modal protocol designed to facilitate a discussion about personal healthcare narratives and the influence of previous generations on health-related attitudes, and to explore the impact of these influences on the current health practices of young African American women.

Findings

Study findings suggest that family narratives do impact health-related decisions. The young African American women in this small, non-representative sample felt that important others in their lives did impact their current health values. Specifically, women acknowledged that they repeated some of the recognized behaviors and verbal messages told to them by people in their circles. Even though all participants were aware of most of the current health practices, not all were practicing healthy behaviors. The data from this study supports the findings of other literature on African American women and health (Davis et al., 2005; Schulz & Lempert, 2004; Brown, et al., 2006).
A narrative approach in the study design was selected to allow for more in depth discussion with participants and the approach did seem to encourage open sharing of important and potentially sensitive information with the researcher.

The study found that the relationships that women categorized as family, core community, and casual community were unrelated to biological connection, but individuals were identified in a category based on the participant’s trust and bond with that person. The women reported that they did learn from both positive and negative behaviors and verbal messages that they experienced with these individuals and felt that those messages related to their current health values and behaviors. Messages clustered around self-care in relation to stress management and tending to illnesses so that health doesn’t decline.

The women who were parents identified having children as influential in their health choices. Most of the women answered “no” when asked if they thought of themselves as “healthy,” although all were practicing preventive health measures and most were engaged with some form of mental health treatment. These findings support the literature that identifies family and community norms and behaviors as key to the development of African American values (Richards, 1997; Goldenberg & Goldenberg, 2008).

In considering the relevant literature on this topic, factors contributing to the findings from this study relate to the family behaviors, environmental factors, and individual change in relation to community norms.

**Family**

All of the participants identified blood relatives, friends, family friends, and extended family members in the family category. Each participant had a unique story to describe why she chose individuals as family or community. All individuals placed in the family category earned
their trust through supporting the study participant’s through a time of need and by providing encouragement and validation of their experiences. The diversity in participant’s family description supports the literature about the composition of African American family. Participants also identified family in relationship to the value of having those mentioned to help them in a time of need. This echoes in literature on African American family structure. Many of the women described how they were able to “get through” a situation because of their families were willing and able to help them.

McGoldrick and Hardy (2008) describe the African American family as resourceful and flexible to meet the needs of its members, developing solutions and connections to help manage the issues as they arise, and this description was easy to see in the women’s descriptions of their own family.

Although problem solving is a necessary tool for survival, one also needs to have established behaviors to avoid crisis. None of the participants described being raised by their families with the knowledge of how to live the healthy lifestyles they want. Many of the healthy qualities participants described were learned from witnessing a family member struggle with illness and health issues related, for example, to not monitoring their diets, attending preventive medical appointments, or exercising. Perhaps, if there were more preventive behaviors instilled in the African American families health practices instead of reactive actions, this pattern described by participants could be avoided.

An illustration of learned health behaviors is shown in a study with 113 African American women who were struggling with obesity and anxiety and found that they were overweight as a child, had overweight parents and/or siblings, and had more psychosocial problems in their family compared with normal weight individuals (Davis et al., 2005). Those
findings support the data from this research that current health practices stem from experiences with family members for African American women. The participants discussed witnessing the health struggles of their parents and grandparents and either (1) also practice the same behaviors, or (2) wanted to live differently so that they did not suffer the same consequences.

**Environmental Factors**

The interviews with participants for this study found that some women saw the negative health behaviors of their family members and were inspired to live a healthier lifestyle. Most of the participants were actively engaged in all but one of the preventive health care activities. The only exception was being tested for glaucoma, which is a largely unrecognized as a risk factor in the African American community (but not in the medical community).

A significant change in the social environment for this generation is access to information through media, including internet and television. The movement to connect people to knowledge about health risks and prevention strategies and solutions has grown exponentially in the last 15 years.

Participants were aware of health risks that their parents and grandparents experienced. Brown, et al. (2004) found that the young African American and African Caribbean women surveyed in Brooklyn, NY, were aware of many of the health risks affecting their population. The researchers discuss the efforts made by organizations such as the Arthur Ashe Institute for Urban Health that go into popular gathering areas (such as barber and beauty shops) to educate the community about health risks. This example demonstrates the work being done to access the African American community. As the women interviewed are all members of the YMCA, they have access to its resources, including those made to engage in healthier lifestyles.
In looking at the larger context of sociopolitical position and how it relates to health, all of the women described being raised at a disadvantage. In their narratives, all the women shared that they grew up in families of a low socioeconomic status. Looking at the differences in behaviors based on age, participants described their older generations as less engaged in healthy living. Due to racism, sexism, and classism, there are many barriers encountered by low-income African American families with regard to meeting their health needs. Shultz and Lempert (2004) found that neighborhood safety, access to healthy foods, education and employment opportunities, and social support and neighborhood integration were all listed as actions needed to improve the health outcomes disparities. Many of these issues were relevant for the study participants as they struggle to live healthier lifestyles, and could be related to their reasons for not identifying as healthy. Participant’s expression of knowledge about what they need to be healthier demonstrates an increased awareness from generations before them.

**Individual Change in Contrast to Community Norms**

Many of the participants identified a loved one whose health was affected by unhealthy choices such as not going to the doctor, not taking time for them self when they felt ill, or eating poorly. This cohort of young AA women decided that they did not want to have the same consequences of chronic illness. All of the women were engaged in preventive healthcare practices and reported that not all of their loved ones were doing the same.

Additionally, many of the women were engaged in some form of professional mental health counseling even when their family and communities advised against it. Some possible connections to the reasons for independent changes from the community norms could be related to the woman’s differentiation from her family, or the stage she is in for her readiness for change. In a study looking at children changing behaviors from their parents, focus groups were
conducted with African American adolescent girls whose mothers were HIV positive (Cederbaum, 2012). The study found that the mother’s HIV status served as a mechanism for behavioral change related to communication about safer sex practices and lower risk behaviors for the adolescent girls. This study demonstrates a child’s ability to learn from a family member’s experience to motivate change in her own life.

**Differentiation**

Many participants reported being engaged in mental health care although their loved ones were against it. It takes a certain quality to follow one’s own values even if it is different from what one has learned in their community. As reported in Goldenberg and Goldenberg (2008), Murray Bowen’s family systems theory looked at the relevance and importance of changing dysfunctional family patterns over time and identified the ability to balance one’s knowledge with their own felt experience as differentiation. One reason for the healthy choices and values of the participants is that they may differ from their loved ones is that they are more differentiated. There are two factors that can contribute to the differentiation of the participants: distance and starting their own families.

**Distance:** Since the majority of participants in the study are not from the Metropolitan Boston area, there is a physical distance from the communities they were raised in. This distance allows access to a new health system and new opportunities to establish how they want to care for themselves. Moving to a new city is a quality of differentiation and supports Bowen’s family system theory. Individuals that value their own uniqueness while maintaining close relationships with significant others in their lives are well differentiated (Skowron, Webster, & Azen, 2004). Based on all of the women’s responses, it can be inferred that members of this group of women have some level of differentiation from their families. All the women are pursuing healthier lives.
regardless of their family members’ choices, while still maintaining a strong sense of connection with those identified in their circles. In a study looking at differentiation in young African American women attending college away from family, the research found that an important factor in the participant’s strong sense of self was the ability to maintain community with their family even with the distance from their families (Skowron, et al., 2004). The strong sense of self that the participants in this study have is demonstrated in the discussion about mental health. There were many participants who described that their families disagreed with going to professional mental health counseling, but felt it was helpful to have a counselor of their own. These participants were able to participate in an activity they felt was best for them while maintaining a relationship with their family members who did not approve of their decision.

Becoming a Parent

Participants that were parents (all but one) reported that the role of motherhood was a crucial factor in their current health behaviors and values. All the mother-participants listed their children in the family category (N=6) and many listed their children when identifying who has been most influential in how they think about health. The women all described becoming more health conscious once they became parents. Participants listed scheduling doctor appointments, cooking healthier, and knowledge of family healthy history as changes they made once they became mothers. The women discussed the importance of being positive role models for their children, or disappointment with others in their communities for not being good role models.

One woman spoke of her partner (the father of her children) and her dismay for his health behaviors, saying, “It’s hard for me to get the kids to want to go to the doctor, when your parent doesn’t want to go at all for anything…even when the kids need to, it is a hassle; they don’t because their father won’t”.

50
This participant identified the connection between a child witnessing a health behavior from a parent and mimicking that behavior. With findings supporting the data of this study, it was identified that parental guidance and clear expectations about drugs and health behaviors are crucial in influencing the values of their children (Reis, 1996). The similarities to this study are in the importance of direct communication from guardians to children about the appropriate behaviors to live a healthy lifestyle. All participants reflected that loved ones who raised them had an influence on their contemporary health values. Some women reported repeating behaviors they learned that helped them live healthy, and some described wanting to raise their children differently than how they were raised.

In interviews with women who were mothers, Young et al. (2008) found that having the role as caretaker created barriers to attending to their own health; time was prioritized for caring for the children and this took precedence over their own needs.

In this study, one participant spoke about wishing that her mother spoke with her about consequences of sex and instead relied on her older brother for guidance in this area. This participant noted that it would be important for her to speak openly about all aspects of health with her daughter when she is old enough. This example demonstrates the point that even though this participant sees things differently now, she was heavily influenced by what she did receive from her family.

**Readiness for Change**

The women identified a variety of qualities that make an individual healthy. Although there were different types of responses, the women all were able to discuss exactly what they felt they needed to do to be healthier. The various responses on what it means to be healthy demonstrate the areas of improvement that each woman saw for herself. Thinking about stages of
change theory, one can see the benefit of conceptualizing the women’s readiness for changing their health behaviors. The women were at different stages of change, but all had a direction in mind of where they would like to get, and some were making efforts toward personal health-related goals.

Schuz, Sniehotta, Mallach, Wiedemann, and Schwarzer used stage theory in their study on dental care outcomes (2009). They found that the key for participants to transition from one stage to another was a strong sense of self-efficacy; that is, to be able to foresee problems and develop solutions. This literature highlights an important factor from this study, specifically that an important element in changing behavior is the ability to know what goal one wants to reach. This point may be the difference between the participants who identified as healthy and those that did not. All the participants had knowledge about what it takes for them to be healthy (however they identified it), but the majority of the women felt that they were not healthy.

Brown, et al., (2006) found that although women were well aware of the health risks, many were still engaged in high-risk behaviors. This literature connects to the data from this study in that for many women, while they knew what they needed to do to be healthy, they had not made the necessary changes (for instance, healthy eating and self care). These same women reported not having health examples set by their families and needed to learn to do these behaviors on their own.

**Implications for Social Work**

This study supports others which have found that there is a connection between what an individual experienced with their family and their own current values. Understanding that there is a familial and community connection with the current health practices and values of this population can be helpful in understanding how to relay information about health and should
influence outreach strategies. This is especially important for the mental health field. This study has shown, and is supported by other research, that many in the African American community do not trust or turn to professional mental health counseling. Some women in this study shared that their families criticized them for engaging in professional mental health counseling. Those in professional mental health settings need to be aware of these challenges that potential participants may face in trying to receive services. There are a variety of ways to receive mental health treatment, and many attempts have been made to make this service more inclusive and accessible to many cultures. This push to be more welcoming is a shift that comes from a history of being seen as an exclusive resource, and can relate to why other family members are against seeking treatment. Ward and Heidrich (2009) support this notion in their survey of African American women across generations who reported learning in their families and communities that it is unsafe to trust professional mental health counselors due to perceived racism, and preferred to be counseled through their religious communities. This may be the key to changing the health statistics that show alarming risks for many illnesses for African American women. Having the knowledge doesn’t seem to be enough, but in addition to being informed, being surrounded by individuals who model the lifestyle that one wants can be a helpful motivator to practice positive health behaviors.

Study Limitations

Research was conducted with only seven individuals, and was drawn from a homogenous population. With more participants, there could have been greater variation in answers, demonstrating a more accurate picture of the larger represented population. Another limitation was in the inclusion criteria of identification as African American. The criteria stated that potential participants must identify as and be experienced in the world as African American. One
of the participants was born in Haiti, but raised in the United States and the people she identified as family were African American. Technically, she can also be identified as Haitian. For future research a more specific definition may be helpful to accurately capture the desired population.

The project faced many feasibility issues, and in the end the sample size was too small to draw meaningful conclusions. The time allotted for data collection was short due to the nature of the assignment (a thesis for a MSW program), and the host site had requirements for when the study could begin that did not align well with school timelines. Finally, specific questions about health histories for participants, and identified influential family members would provide more extensive data to trace patterns of health behaviors, such as illness, obesity, and substance use. Having this information would be helpful to further understand the backgrounds of participants with the challenges in making changes in their behaviors.

**Study Strengths**

An important aim of this small exploratory study was to pilot an innovative, multi-modal protocol designed to facilitate a discussion about personal healthcare narratives and the influence of previous generations on health-related attitudes. The protocol was very successful in providing a structure for case study type interviews, and used methods that may be transferrable to both the clinical and research setting. The interactive nature of the protocol helped to facilitate detailed discussion and was a relatively easy way to capture data for later analysis. Participants described a wide range of relatives and associates within their circles of influence.

**Recommendations**

This is an important area for research. Further studies exploring the trans-generational transmission of health care values and beliefs in the African American community may provide additional insight into strategies for reducing the dreadful health outcomes disparities that face
our nation. Having a larger number of participants and collecting more family and personal
histories will provide more enriching data to strengthen the study.

Conclusion

This study found that there is an impact from the experiences with family and community
members on the health values and practices of young African American women. Recognizing
and utilizing the importance of family in the health choices of young African American women
can strengthen the relationship between clinician and client. Due to the limitations in the study,
there can be further research in the relationships about the impact of messages and behaviors of
family members on health practices and values. Findings from this study can be used to
strengthen approaches in decreasing harmful health risks for African American women.
References


Appendix A

Recruitment Flyer
Who has had the most influence on your health-related views and practices?

Did health-related messages you learned growing up shape how you take care of your health today?

These are some of the questions that the Family Circles research study is exploring. This HSR approved research is taking place right here at the Boston YMCA. We are especially interested in the experiences of young women of color.

If you are a YMCA member, 19-30 years of age, identify as African American, and are willing to meet with a researcher for about 45 minutes to share your story, we would love to have you sign up. Interviews will be held here at a time convenient for you.

To learn more about the study and how to enroll, please call, text, or email Liz Love.
Appendix B

Letter of Support from Sponsoring Institution
January 9, 2013

Smith College
School for Social Work
Lilly Hall
Northampton, MA 01063

To Whom It May Concern:

Families in Transition gives permission for Elizabeth Love to locate his/her research in this agency (institution). We do not have a Human Subjects Review Board and, therefore, request that Smith College School for Social Work’s (SSW) Human Subject Review Committee (HSR) perform a review of the research proposed by Elizabeth Love. Families in Transition will abide by the standards related to the protection of all participants in the research approved by SSW HSR Committee.

Sincerely,

[Signature]

David N. Tavares, Associate Director of Housing

Location address removed to protect enrollee confidentiality.
Appendix C

Informed Consent
Letter of Informed Consent

Study name: Healthcare narratives across the generations and their impact on the health-related practices of young African American women

Study overview: My name is Liz Love. I am a graduate student at Smith College School for Social Work. You are here today because you have expressed an interest in enrolling in a research study that will explore the influence of previous generations on the health-related attitudes and practices of young African American women.

There is some research which suggests that healthcare messages and practices may be passed from generation to generation, but there has not been a lot of research on this topic, and we don’t know if this is true. There are no studies that have explored cross-generational influences on the healthcare practices of young African American women. We think that this is an important topic to learn more about.

If you decide to participate in the study after reading this letter of informed consent, we can start the interview. It will be more of a discussion than an interview. We will meet for about 45 minutes. To facilitate our discussion, we will use a “circles board,” a large diagram, to help capture information about important family and community members who may have influenced how you think about your own health. After you complete the “circles” exercise, the board will photographed for later analysis. If you agree, a 10 minute segment of our discussion will be digitally recorded. I will listen to the recording later and transcribe our conversation so that I don’t miss any details. I will be the only person to see and analyze the “circles” photographs, and I will be the only person who listens to recordings of our discussion, and I am the only one who will have access to my written notes.

Who can participate? In order to enroll in the study you must be at least 18 years old and not have reached your 31st birthday. You must be English speaking and identify and be experienced in the world as African American. In addition, you must be enrolled in a program at the Boston-Y, or be a staff member at the “Y.”

Potential risks of participation. The nature of the research interview is to gather information about your social supports, health beliefs and practices, including healthcare utilization, unmet needs for healthcare, and self-reported barriers to accessing health care. Given
this context, there is a risk that some participants may experience emotional discomfort or stress, especially if they are worried about a health problem and are having trouble finding healthcare resources that they can afford. To address this possibility, a list of free health-related resources can be found at the bottom of this letter, should you need them.

**Potential benefits of participation.** You will not receive any money or other compensation for your participation. You may gain new perspectives about the influences that help to shape your ideas about health and your healthcare practices. It is possible that you may derive some satisfaction from knowing that you contributed to a study that may someday help other African American women make informed decisions about their healthcare.

**Participation in this study is anonymous.** Safeguards have been put in place so that only the researcher will know the identity of study participants. That means that no one will know that you have taken part in the study unless you tell them yourself. Of special importance, no one at the “Y” will know if you did, or did not, participate in the study.

**Your information is treated confidentially.** The information you share here will be safeguarded and treated confidentially. Safeguards have been put in place to protect your confidentiality; no personally identifying information will be asked for or entered into the data set. The report written up about the research will aggregate findings; that means that written reports about the project will describe what was learned about the practices of a large group of women, not about each individual woman.

Data from the study will be kept in a secure location for a period of three years as required by Federal research guidelines. It will be destroyed after that time unless the data are important to keep for ongoing research. If so, the data will be destroyed when it is no longer needed for research. Data that has been stored electronically will be kept on password encrypted media; only the study investigator will know the password. Paper documents will be similarly protected and kept in a locked file cabinet under the investigators sole control.

**Participation in this study is voluntary.** You may choose not to participate in the study after reading this informed consent; your interview will end. You may choose to enroll and start the interview but decide later that you don’t want to complete the interview. You may skip any questions you don’t want to answer; you can stop the interview at any time; you can end the interview. You can complete the study and later decide that you want to withdraw from the study. This is possible if your request is received on or before April 30, 2013. After that date,
the data will have been aggregated and I won’t know which data are yours and which belong to other participants, so it would not be possible to take out your data.

Should you have any concerns about your rights or any aspect of the study, you can call me, or you can contact the Chair of the Smith College School for Social Work Human Subjects Review Committee: 1 (413) 585-7974
Researcher, Elizabeth Love: 1 (XXX) XXX-XXXX

A list of free healthcare resources appears on the next 2 pages.
LIST OF HEALTH RESOURCES

WOMEN'S HEALTH NETWORK
Department of Public Health
250 Washington Street, 4th Floor
Boston, MA 02108-4619

  Information and Referral: (877) 414-4447 | (617) 624-5406
  Languages: English, Spanish, Portuguese
  Email: DPH.WHN@state.ma.us
  Web Site: http://www.mass.gov/dph/whn

Breast and cervical cancer screening, colorectal cancer screening, diagnostic services, health
education, patient navigation and case management services to low income, uninsured or
underinsured women. These services are provided through a network of local health centers,
hospital based clinics and community agencies throughout Massachusetts.

MASSACHUSETTS MAMMOGRAPHY PROJECT
  Online information about how and where to get free and low cost services.
  http://massmammograph.com

COUNSELING, TESTING & SUPPORT RESOURCES
INFECTIONOUS DISEASE BUREAU
(617) 534-4559 | Email: aids@bphc.org

HIV Counseling and Testing is a crucial component to routine healthcare. To protect yourself
and your partner, it is important to get tested regularly. Talk with your doctor about HIV
testing. Or, through the links listed to the right, you can find the testing site nearest you, many of
which offer free counseling and testing services. Testing is easy and takes only a few minutes.

WALK-IN SUBSTANCE ABUSE TRIAGE, ASSESSMENT RESOURCES
AND REFERRAL CENTER
Boston Public Health Commission

774 Albany Street | Boston, MA 02118
1 (617) 534-5554 to make a referral or receive additional information

The Resources and Referral Center (also known as Central Intake) is a walk-in substance
abuse triage and assessment service that provides referrals to outpatient counseling,
acupuncture, and opioid treatment services. The Center also makes referrals for
detoxification and residential programs to other agencies in Boston.

Hours are Monday through Thursday from 7:00 AM to 3:00 PM.
Appendix D

Interview Guide
INTERVIEW GUIDE

MATERIALS TO HAVE IN THE INTERVIEW ROOM
1. “Circles” Poster
2. Some sort of easel to place the Poster on.
3. Black felt tip pens.
4. “Sticky” posts, preferably cut circular, in 3 different colors.
5. 2 chairs
6. Lap table or table to write on.
7. Camera
8. Digital recorder
9. Easel to hold the “circles poster”

MEET THE PARTICIPANT
Greet the participant → “Hello, thank you for agreeing to meet with me. Our meeting today should take about 45 minutes, but first I need you to read and sign this consent form before we begin. If you prefer I can read it out loud as you review it and can answer any questions.”
→ Review the Informed Consent.
→ Read it out loud to the woman if she prefers (literacy level).
→ Ask if she has any questions.
→ After the informed consent is signed, proceed to the interview.
→ If the woman prefers not to participate after reviewing the informed consent → “thank you for your interest and your time so far. Have a good day”.

INTRODUCE THE TASK
“One will be using some materials today for our meeting”.
→ Show her the “Circles Poster” and then place it on the easel.
→ Confirm that she is seated close enough to be able to see the poster easily.

SUPPORT MAPPING
“This task is to help visualize the important people in your life.”
→ Look together at the “Circles” poster.

EXPLAIN: “The inside circle represents people that you consider FAMILY. This may include anyone that you think of as ‘family’.”

“Your CORE COMMUNITY may be people that you feel close to or whom you rely on, or institutions (such as Church, the Y Program), but who are not family members.”
“Your CASUAL COMMUNITY may be people that you know or see from time to time. Someone you might call on or who has helped you.”

THE FIRST TASK: CONSTRUCT A LIST
Goal: Develop a list of members of the woman’s circle

TASK 1: “Our first task is to write the names of people in your FAMILY. Just a first name is all you need to write. I have some sticky paper here, cut into circles”. [SHOW]

ILLUSTRATE: “I will show you as an example”, “I will fill out a “sticky” with the name “Pat.” → Write clearly (remember, you will be taking a photo of the Board for later analysis). → Place the circle on the BOARD.

INSTRUCTIONS: “Now, I would like for you to write the first name of people you consider to be “family.” One name on each “sticky.”
→ Ask the woman to fill out a “sticky.” → As each circle is completed, put it on the Board.

• PROMPT: Families come in many forms. Sometimes those whom we call “family” are related to us. Sometimes people we consider “family” are not related. This could be relatives or neighbor, co-worker, boss-employee, pastor-church member, teacher-student, etc. community members; whomever you consider family.

• These may be people that you call in times of crisis, or to share exciting news. These may be people you trust most. They are whomever YOU call FAMILY.

REPEAT ABOVE until the woman says that there is no one else to list in her FAMILY.

___________________________________

CORE COMMUNITY: As above, asking the woman to write the names of people whom she feels are in her CORE COMMUNITY. If she asks for clarification, indicate:

• PROMPT: Your CORE COMMUNITY may be people that you feel close to or whom you rely on. This could be relatives or neighbor, co-worker, boss-employee, pastor-church member, teacher-student, etc. community members; whomever you consider in your core community.

• These may be people whom you have open communication with, you just may not speak to them as often as you’d like or they are not the first to know what is going on with you.

REPEAT ABOVE until the woman says that there is no one else to list in her CORE COMMUNITY.

___________________________________

CASUAL COMMUNITY: As above, ask the woman to write the names/roles of people whom she would place in her CASUAL COMMUNITY.

• PROMPT: Your CASUAL COMMUNITY may be people that you know or see from time to time. Someone you might call on or who has helped you.
• These may be people who have helped you or touched your life in a way that has had meaning to you, even if you don’t speak to them frequently.

THE 2ND TASK: IDENTIFY THE RELATIONSHIPS
The goal is to identify relationships (Mother, father, sibling, aunt, uncle, grandparent, church member, etc.) of members or the circle. There is already have a first name, in this part you will add the relationship to the “sticky.”

EXPLAIN: “Next, we are going to look at each “circle” and write how each person in your Circle is related to you. For example, if this is kin, you might indicate “mother,” or “sister” or whatever the relation. Or the person could be a neighbor, co-worker, boss-employee, pastor-church member, teacher-student, etc.”

ILLUSTRATE ➔ Remove the “Pat” sticky from the Board and write AUNT on the same piece of paper and place it back on the Board. DISCUSS WHAT JUST DID. Take it back and write MATERNAL Aunt.

The woman can write the relationship on the “sticky,” or tell the interviewer who will do the writing.

➔ Look at the Board together. ASK: Is there anyone else that you want to add?
➔ Take a photograph of the Board. Check to be sure that the photo is legible.

THE 3RD TASK: IDENTIFY 3 PEOPLE FROM THE CIRCLE WHO HAVE BEEN THE MOST INFLUENTIAL WITH REGARD TO HOW SHE THINKS ABOUT HEALTH AND SELF CARE.
The goal of this part of the interview is to have the women identify who has been the most influential with regard to how she thinks about her health and the kind of health care she receives.

INSTRUCTIONS: “I would like to ask you to look at YOUR Circles Board again with me.” ➔ LOOK AT THE BOARD TOGETHER. The next questions are specifically about your health and health care as an African American woman.

➔ “Can you pick one person from this group who has had a big impact on how you think about taking care of your health?”
  • PROMPT: “Perhaps it is someone who led by example, who took good care of their own health.”
  • “Or, perhaps it is someone who has given you advice about your health and healthcare. Someone who has influenced how you take care of yourself.”

➔ “Can you pick another two person from the group who has had a big impact on how you think about taking care of your health?”

➔ REPEAT ABOVE UNTIL THE WOMAN HAS SELECTED 3 PEOPLE ➡
If we stop at 3 people, will it leave out anyone who was an important influence on your health and self care? [If “yes,” continue to collect information].

**THE 4TH TASK: EXPLORE THE INFLUENCES**

The goal of this part of the interview is to have the women describe the kinds of influences the 3 people they selected have had on their health.

Three women have been selected from the woman’s Circles as being influential with regard to her ideas about health and personal health care.

<table>
<thead>
<tr>
<th>Name</th>
<th>Circle (1=Family; 2=Core Comm; 3=Casual Comm)</th>
<th>Relation-ship</th>
<th>Describe what the woman learned from this person about health and caring for her own health. How was the information conveyed? By example; by talking? Help at a critical health time?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
**TASK 5**  
**Recommended Healthcare**  
Use this grid to capture the “routine” health care screenings the woman has had, and also the screenings that her 3 closest people have had (if she knows).

<table>
<thead>
<tr>
<th>Have you . . .</th>
<th>Woman</th>
<th>Rel #1</th>
<th>Rel #2</th>
<th>Rel #3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gone to get a check up at the doctors in the last 3 years for reasons other than being sick?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Do you do breast self exams?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Do you see a gynecologist or PCP every year for a pelvic exam/ pap smear?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Have you talked to a doctor about the HPV virus?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Have you talked to a doctor about STD and HIV testing?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Have you talked to a doctor about safer sex practices?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Have you ever been to an eye doctor and been tested for glaucoma?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
TASK 6: TRANSCRIPTION | MENTAL HEALTH

1. What have the people in your circle suggested that you do when you feel sad?

2. Have you gotten any advice about who you might talk to about these feelings?

3. How do members of your circle view professional mental health counseling?

4. What have been some of the ways that people in your circle have said or shown you about how to handle stress?

5. What are qualities you identify in a healthy person? Do you consider yourself a healthy person?
Appendix E

Smith College HSR Approval Letter
March 14, 2013

Elizabeth Love

Dear Liz,

Thank you for making all the requested changes to your Human Subjects Review application. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, the following requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Marsha Klone Pruett, M.S., Ph.D., M.S.L.
Acting Chair, Human Subjects Review Committee

CC: Elizabeth Irvin, Research Advisor