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Ethnic Notions & Healthy Paranoias:

Understanding of the Context of Experience and Interpretations of Healthcare Encounters among Older Black Women1

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Abstract

Objectives—To report the firsthand perspectives of older Black women within healthcare encounters that impact the trajectories of health seeking behavior; to examine their perceptions, expectations, and beliefs about the role of cultural difference within predominantly White (US) health care settings; and to explore how sharing personal experiences (theirs and others') as a fund of knowledge influences ethnic notions. This research is aimed at the development of community resource partnerships and effective healthcare service delivery with intervention and promotion efforts targeting older Black women.

Design—Ethnographic data collected over a twenty-four month period (2003 – 2005) from fifty older Black women in Tucson, Arizona is discussed on three levels: (1) expectations and beliefs, (2) the use of ethnic notions in the form of healthy paranoias as part of individual and communal health advocacy, and (3) perceptions of interethnic communication within healthcare settings, including feeling uncared for by healthcare providers and support staff.

Results—Disparities in older Black women's health and well-being are often constructed and filtered through "non-clinical" influences, such as cultural differences, individual experiences, and beliefs about "race" or "being" a Black female.

Conclusions—Unfamiliarity with ethnic notions may cause misinterpretations and misunderstandings and may influence interactions between older Black women and healthcare providers.

Keywords

race; older black women; ethnic notions; healthcare; 'having to fight'; interethnic communication; funds of knowledge and healthy paranoias

Introduction

Overview

In recent years, life expectancy and overall health status have improved for a majority of older American women, due partly to advances in medical technology and increased focus on preventive healthcare screening programs (Krieger 2002). However, despite continued advances in health care and technology, older African American women (≥ 40 years of age) still experience more disease, disability, and premature death than White women in the same

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age group, regardless of income, education, or insurance status (Geiger 2002, National Center for Health Statistics 2007). Racial classification in the U.S. sustains ethnoculturally specific beliefs about difference, and we do not fully understand the impact of these non-clinical influences on interactions within healthcare settings and healthcare/clinical encounters (Omi & Winant 1999). These interactions and encounters among older Black women, healthcare providers, and support staff seem to be critical elements in this population's ability to mediate risk factors to their health and well being and to ensure provision of the best possible patient-centered care.

This article explores interactions and encounters that seem to indicate ethnocultural difference and perceptions about "race" deriving from ethnographic data collected among fifty Black women (≥ 40 years of age) between 2003 – 2005 in Tucson, Arizona. The goals were to report the firsthand perspectives of older Black women within healthcare/clinical encounters that impacted the trajectories of their health-seeking behavior. Their access to and utilization of screening exams for breast and cervical cancer was the case study used to collect their "points of view," which emerged from self-reported experiences, clinical interactions, and healthcare encounters within (predominantly White) healthcare settings. In the interviews, particular attention was also given to their experiences when interacting with healthcare providers and the health care system throughout their lives, as these experiences may have impacted the trajectories of their health behavior, as well as the health behavior of others.

In U.S. society, "race" matters both as an objective condition and as an ontological and ideological axis of differentiation that has real effects on Black people's lives, e.g., "categories of the mind and categories of power" [2] (Hirschfeld 1997). "Racial" identity and racial signification are socially constructed inventions that condition and create many sociocultural environments for racial/ethnic populations. "Being" Black in the U.S. is a social construct reinforced by law that makes "race" real at the site of Black bodies; Black women are still regarded by the larger society as the natural expression of a "race"(Omi 2002). Today *Blackness*, as an inappropriate "otherness," is represented by the African American body and has become a "race" in totality, an ethnicity separate from and considered inferior to Whites. Thus the historical embeddedness of "race" as both a "sign" and a "signifier" is part of the cultural ethos of Black experience [3] among many older women in my study (Kehoe 2000, Kington *et al* 2000,Caldwell & Jefferson 2002,Jones 2002,Freeman 2003,Ryan *et al* 2006).

African American Women in the United States

Slightly more than 18 million (12.7 %) females living in the United States are African American. This population also has a higher proportion of older female adults than many other racial/ethnic sub-populations. In general, older Black women outnumber older Black men. These women are more likely than others to be widowed, and the longer they live, the more likely they are to be affected by chronic illness, disability, and dependency(National Institute on Aging 2006 [NIA]).

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[2] Hirschfeld, L. The Conceptual Politics of Race: Lessons from Our Children. *Ethos*, 1997, 25 (1):63–92. Hirschfeld's (1997) discussion of "race as a category of the mind and/or a category of power" specifically notes that identity by "race" is part our social fabric, as a category of the mind among Whites and African Americans. Being predisposed to be on the receiving end of various acts of racial bias such as discrimination, segregation, or physical attack is often part of a socialized, and culturally shared "unquestioned belief" due to the racial status of "being" Black in U.S. society. In other words, as a category of the mind -- racial bias may be "out of sight but never out of mind" for Blacks (defined by Earl V Pollard, personal communication, 2002).

[3] Kehoe P. Race and Medicine: The Black Experience. *In* : B. Lang, ed. *Race and Racism in Theory and Practice*. Lanham: Rowman & Littlefield ; 2000, P.229–242. The term Black experience is used in this paper to refer to experiences in healthcare/clinical encounters and interactions with the health care system as perceived by the older Black women. These were often specifically focused on how the use of racial stereotypes emerged as disrespectful / inconsiderate treatment or their perceptions of discriminatory practices in those settings.

Black women (≥ 40 years of age) are at particularly high risk for chronic illness such as diabetes, cancer, hypertension, and increased disabling conditions as they age. Thus, race/ethnicity, age, and gender can be perceived as fundamental measures of exposure to increased health risks. In the US, Black racial status may also be an important risk marker for exposures to racism and could be one of the main etiological factors producing inequitable "race" differences in morbidity and mortality (LaViest 2000).

Nationally, an examination by race/ethnicity of age-adjusted mortality rates for women, for all causes, reveals that despite declining death rates over time, Black women have consistently had higher mortality rates than White women; for example, African American women generally have the highest age-adjusted death rates for heart disease, cancer, diabetes, and HIV/AIDS (Kaiser Family Foundation 2009, National Center on Minority Health Disparities 2009).

In recent years, life expectancy and overall health status have improved for most non-minority women, due partly to advances in medical technology and increased focus on preventive healthcare screening programs. However, even though Black women experience many of the same health problems as White women, as a group they seem to be in much poorer health, use fewer health services, and continue to suffer disproportionately from premature death, chronic disease, and disabilities than White women in the same age group, regardless of income, education, or insurance status (Krieger 2000). According to Geronimus (2001, p.133):

> …African American women experience early health deterioration as a consequence of cumulative and repeated experiences of exclusion…and continue to experience health outcomes that suggest, at least metaphorically, an accelerated aging process…

Local and national mortality data in 2001 showed the average life expectancy at birth for an African American woman was 74.7 years, with White women exceeding this estimate by almost 6 years (US Bureau of the Census - Vital Statistics 2001, Arizona Department of Health Services 2005 [ADHS]).

Non-Clinical Influences

Who and what are responsible for population patterns of health, disease, and well-being as manifested in present, past, and changing sociocultural health inequalities? Clinical encounters often reflect ethnocultural tensions and may be enacted in racial terms, particularly in the US when the actors are Black and White. Therefore, what kinds of difference constitute "race" and what difference "race" makes with respect to an older Black woman seeking care and to a healthcare provider delivering that care are pivotal questions that are explored in this paper.

Racial identity is a socially constructed reality in US society that is "typically measured by skin color and a handful of other easily visible physical characteristics "(LaVeist, 2000, p.217). In the US, races are recognized, constructed and contested, and where situations make it possible (or force) people to have experiences that may or may not be positive. Thus, according to Geiger (2002, p. 440):

> …it seems reasonable to conclude that neither the health care system as a whole nor individual providers are fully insulated from attitudes toward race…that are prevalent (though often unacknowledged) in the larger society…

Health inequities (disparities) often result from perceptions, expectations and beliefs held by patients and healthcare providers, e.g., ambivalent feelings about healthcare encounters that are perceived as hostile/disrespectful to Black people may increase "biopsychosociocultural" stress, decrease the number of provider's recommendations to patients and result in poorly controlled chronic health conditions (Bailey, 2000). Many of the inequities in older Black women's health and well-being may be constructed and filtered through non-clinical influences, such as ethnocultural differences, individual experiences, and beliefs about race/ethnicity (Geiger, 2000, 2002).

As discussed by several authors (Cornell & Hartmann 1998, Davis 2002, Omi & Winant 1999), "race," i.e., "being" Black or African American has become a "multidimensional mixture" of the categories of "race" and ethnicity as noted by Smelser, *et al.* (2001, p.3),

> …race is a social category based on the identification of (1) a physical marker transmitted through reproduction and (2) individual, group, and cultural attributes associated with that marker. Defined as such, race is, then, a form of ethnicity, but distinguished from other forms of ethnicity by the identification of distinguishing physical characteristics, which, among other things, make it difficult for members of the group to change their identity…

Racial categories are constantly being formed, transformed, reformed, or destroyed in reflection of economic, sociocultural and historical processes operating across and through time, in which the U.S. has been the preeminent site of production. Krieger (2000) cites a growing body of evidence suggesting that "economic as well as noneconomic aspects of racial discrimination are embodied and harm health across the life course" (p. 211). Thus it is reasonable to suggest that Black women may experience a disproportionate number of health inequities (disparities). "Race," like Blackness, is a social status category created by macrosocial factors. Racial obstacles are such a part of Black lives that they have become acknowledged, even accepted parts of the ethnocultural woodwork. The durability of an identity by "race" in our post-civil rights climate derives from the creation of new racial subjects and the significant transformation of existing ones: “far from declining in significance, the racial dimensions of…social life have grown” (Omi & Winant, 1999, p.53). Countless people have attempted to define and interpret the identity of formerly enslaved Africans as Americans. I suggest that no definition of a people has been more oppressive or long-lasting than the ideological and sociocultural interpretations of Black people as representing a separate “race" of humanity. Thus, "race" is really about how people assign different meaning and value to an individual’s physical appearance, assuming appearance can predict behavior.

"Race" matters because it is both an enigma and a stigma. Overwhelming evidence suggests that there exists an inequality in the quality of health care delivered to "racialized" populations (Krupat *et al.* 1999, IOM 2002). According to Helman (2001), having different bodies often subjects people to considerable stigma, including "well-meaning" racism. For example, the Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care offered evidence from *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* of doctors describing Blacks as "lazy, less intelligent, less educated, less likely to comply with medical advice and more likely to abuse drugs and alcohol" (Smedley *et al.* 2003).

If we agree with Hahn (1990) that how a society is organized affects not only what health conditions people acquire and continue to suffer from, but who gets which ones, how sick persons and their conditions are perceived, and what is done in response to sickness, and with Smelser, *et al* (2001, p. 3), who noted that "something is contributing to a real difference in the way minorities are being treated in the health care system," then patterns of health behavior among older Black women in relation to their access and utilization of healthcare and the delivery of optimal service to them by healthcare providers must be explored by examining cues to behavior that may be grounded in misconceptions about the genre of difference.

Patient-Centeredness

Societal ideas about "race" may well be so deeply embedded in the fabric of both Black and White consciousness that they have become influential within healthcare settings in (a) delivery of patient-centered quality care, and (b) timely access and utilization of care. Patient-centered perspectives look at how patients interact with the health care system and how the health care system supports patients while considering their ethnocultural traditions, personal preferences and values, family situations, and lifestyles. Patient-provider communication and interactions that occur within healthcare encounters, for example, the manner in which ethnocultural differences are perceived and how interethnic communications are understood when framed around a "racial" identity, may be critical elements of patient-centeredness, as these impact the patient's ability to stay healthy, get better, or live with illness or disability. Patient-centered care ensures patients transition easily between providers, departments, and healthcare settings and that those transitions are respectful, coordinated, safe and efficient (Agency for Healthcare Research and Quality [AHRQ] 2007).

This paper focuses on providing information to improve the quality of care received by older Black women. The Institute of Medicine has designated patient-centered care—care that is respectful of and responsive to individual patient preferences, needs, and values—as one of six domains of quality. These domains include access to care, communications, quality improvement, coordination of care, care management, and self-management. It is critical that providers, in their practices and healthcare settings, evaluate and improve care, particularly in regard to what patients feel they need. The development and implementation of health interventions, education, and promotion efforts must include a contextual understanding of the experience and interpretations of healthcare/clinical encounters among racial/ethnic minority groups.

Ethnographic Approach

Using sociocultural constructionist/constructivist approaches[4] (Bernard 2000, Lincoln & Guba 2000) and guided by ecological perspectives (Berkman & Kawachi, 2000) I was able to uncover some of the layers of context and significance in the healthcare experiences of older Black women. My approach provided strong theoretical platforms for exploring the diverse elements of difference identified during this ethnographic research. For example, during interviews I explored how, when, where, and why older Black women may have felt the need to utilize ethnocultural categories in healthcare encounters.

While I do not agree with those who suggest that "being" Black or having a "race" signifies any one set of homogeneous practices or experiences, as Dominguez (1989, p.12) notes, "being" Black in the U.S. is defined as having an identity determined by "race," a kind of "disputed identity of [being both] a subject and [an] object," i.e., as simultaneously occupying the status of "race" and ethnicity. And although the women I interviewed were born and came of age in a range of geographic, cultural and historical contexts, they seemed to share a common ethnocultural understanding of experiences of racial bias, segregation, discrimination, and the struggle for equal rights (Williams 1999, Bailey 2000, Link & Phelan 2000).

Ethnic Notions and Healthy Paranoias

I use two sociocultural constructs, *ethnic notions* and *healthy paranoias*, as metaphorical expressions to describe many of the non-clinical influences that emerged through analysis of the ethnographic data. These constructs guide the rest of this paper's discussion of the sharing that occurs among older Black women regarding personal experiences in healthcare settings, including perceptions, expectations, and beliefs. These experiences add to an ethnocultural

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[4] Crotty M., 1998. The Foundations of Social Research: Meaning and Perspective in the Research Process. London: Sage. P.58. Constructionism shapes the way in which we see things (even in the way we feel things) …and gives us quite a different view of the world…constructivism is the capacity to construct reality…it is the meaning making activity…how we are interpreting and constructing reality. The perspectives offered by both sociocultural constructionism and constructivism proved most useful in the analysis and interpretation of the data for this ethnography.

fund of knowledge that may serve to intensify one (ethnic notions), thereby substantiating the need for the other (healthy paranoias).

The first construct, *ethnic notions*, is a term borrowed from Marlin Riggs' 1991[1987] ground-breaking documentary film entitled *Ethnic Notions*, which explored the evolution of racial consciousness in America and examined deep-rooted stereotypes which fueled anti-Black prejudice. In my study, an *ethnic notion* refers to subtle shifts in the interpretation of intention, ethnocultural difference, and context that may occur during healthcare encounters from the perspectives of older Black women. *Ethnic notions* may also represent shared perceptions, expectations, and beliefs within healthcare settings and among healthcare providers, thereby influencing the delivery of optimal care. Specifically, healthcare providers hold positions of power in most clinical encounters and are themselves influenced through their training, education, and personal perspectives on underlying health behaviors, challenges, risks, patterns of morbidity, and mortality. Thus, *ethnic notions* have implications for the receipt of patient-centered quality care.

The second construct, *healthy paranoias*, comes from a conversation with a Black social psychologist on the cultural significance and value of practices of hyper-vigilance among some Blacks as *healthy* while at the same time representing *paranoia* (Wiggins 2003). Among some older Black women, *healthy paranoias* were protective factors based on earned suspicion and mistrust drawn from experiences within both pre-and post-civil rights healthcare systems in the U.S. In her essay entitled *Why it's Not Just Paranoia, Newsweek Magazine* contributing editor Lorene Cary (1992, p.23) explains what I have termed *healthy paranoias* regarding some Whites:

> … Americans continue to value the lives and humanity of some groups more than the lives and humanity of others. It is our historical legacy and present fact; it influences the daily interactions of millions of Americans with Black people. That is not paranoia.

A *healthy* paranoia may serve to modify health behaviors over time because older Black women or others in their networks of support have personally faced racial profiling and poor or disrespectful treatment in their daily lives. I do not suggest that every single healthcare encounter within a predominantly White healthcare setting can be considered to have negatively impacted older Black women, nor that every encounter results in racial bias. However, I do propose that many older Black women share a group condition of oppression and an awareness of it that has led to the development of *healthy paranoias*.

My participants discussed their need to be hyper-vigilant while receiving healthcare services and the suspicions that they generally had of the health care system. Those concerns were often labeled by others as "hypersensitivity," a term with negative connotations of "being unreasonable or difficult," i.e. paranoid. However, among many of the women in my study, being skeptical and suspicious was unquestionably reasonable because such attitudes were validated through their actual experiences. My ethnographic data suggests that this hyper-vigilance is actually a *healthy paranoia* with components of self-preservation, awareness and self-advocacy, providing resiliency.

Many members of the African American community are "already alienated from the health care system," according to Thomas & Quinn (1991, p.1499). Certain aspects of *healthy paranoia* or an *ethnic notion* may influence the actual health practices of older Black women, increasing the risk of late diagnosis or receipt of less than optimal care. Additionally, older Black women may expect that healthcare encounters can actually be detrimental to African Americans, a perspective that may keep older Black women from participating in health and medical research and even from donating organs. An *ethnic notion* or *healthy paranoia* may include aspects of their own encounters, personally witnessed encounters of others, or those shared with them by other Black women.

It was critical in my study to acknowledge the diversity of each older Black woman's individual experience, within healthcare encounters and within the broad category of having a racial identity, as non-clinical influences of ethnocultural differences which seemed to impact patterns of health behavior, i.e., as the reciprocal relationships of (a) the cultural ethos of the health care system and (b) the cultural ethos of older Black women. Furthermore, non-clinical influences as ethnocultural differences that reference the Black experience may become enabling or predisposing factors before the healthcare encounter occurs (Sims 2006).

Pearce (1993), in discussing how lay medical and health knowledge is shared among Blacks, agrees with Hoffman-Goetz & Mills (1997), Chavez, *et al.* (2001), Chavez (2003) on the need for healthcare providers to recognize relevant reflexive cultural components within healthcare settings as critical elements in identifying the presence and importance of ethnocultural differences. By being appropriately cognizant of and responsive to cultural issues, healthcare providers may be more able to mediate risks to health and well being. If respectful partnerships are to be developed among older Black women and healthcare providers, then *healthy paranoias* and *ethnic notions* must be acknowledged as elements of ethnocultural differences and as non-clinical influences. These are quality of care issues since both constructs have implications for access, utilization, and receipt and delivery of optimal care.

Methods

Recruitment of Study Participants

Recruitment began with key informants (n=8), Black women (≥ 40 years of age) widely known and respected in the local community. This data was used to determine questions that might be relevant among a larger sample of older Black women as part of developing an interview guide. Using a sociocultural network sampling strategy, I asked Black women I knew or who were in the key informant pool to make referrals and announcement and to hand out flyers at neighborhood, cultural, and community events and at health conferences. Such occasions are often places where information is accessed and shared in a city with no newspapers or print media specifically focusing on the Black community. I also made presentations about my proposed research at many such events.

Each woman who showed interest in my study was required to fill out a permission to call card, with her name, phone number, and the best time for me to call. I also use this document to collect data on ages and "racial" identity, which enabled me to eliminate those who did not meet the criteria (African-American, female and ≥ 40 years of age) for the study. Seventy-five of 125 interested women met the study criteria. Fifteen of those women declined to participate further. Of the sixty women remaining, 35 agreed to participate as a sample population of older Black women, and in-depth interviews were scheduled. As with the key informant pool, quantitative data was collected from this population on their existing patterns of health behavior, personal health care regimens, and demographic data, which also included collecting information on health, diet, and exercise behavior.

Although it was fairly easy to recruit participants who were active in church, civic, cultural, and social venues, I also wanted to collect data from women who were not involved in such organizations and/or activities. These women proved difficult to locate because they are residentially scattered and there is no centralized geographic site that can called the Black neighborhood in Tucson, Arizona. Thus, the women who participated in my study were drawn from residentially dispersed sites that represented anywhere from 3.0 to 14.0 percent concentrations of the African American population in Tucson, Arizona (City of Tucson Urban Planning and Design 2004).

Data Collection

Ethnographic data was collected from fifty Black women over 40 years of age (2% of the age-eligible population) residing in Tucson, Arizona. The interview process was pilot tested among key informants (n=8) prior to implementing the study with the larger sample (n =35), followed by a post-study discussion group among women (n =7) who had not participated in the study. The interview guide was developed based on issues emerging from key informant discussions, healthcare provider self-reports, and ongoing review of the literature. At the end of the study and prior to analysis of the data, a discussion group was conducted to explore some of the observations and opinions raised by key informants and interviews from the larger sample.

Individual interviews and group discussions among the women lasted from 2.0–2.5 hours each. Women were encouraged to discuss the significance of communal and individual perceptions, expectations, and beliefs about healthcare that they thought might be part of shared understandings prevalent among older Black women. Interviews also explored how these factors might influence health outcomes. They discussed patterns of behavior and person-to-person interactions, the type of treatment perceived, expected, or experienced within healthcare settings, and their own encounters with healthcare providers and support staff in those settings. None of the study participants were paid for participation in this study. All the study participants were recruited over a period of 15 months and individual interviews were conducted over a 2-year period. All interviews/discussions were audiotaped and transcribed.

Background interviews were conducted to collect secondary data from healthcare providers (n = 8) who interacted with older Black women, with each interview lasting about 1.0 hour. Providers worked in either public or private healthcare settings. Each healthcare provider was previously identified from various public/private and community health networks in Tucson and from referrals by key informants. Racial/ethnic identity, age or gender were not among the criteria for healthcare providers to participate; however, it should be noted that although gender was not a requirement for participation, all the healthcare providers were female. In addition, although race/ethnic identity was not a requirement for participation, three were Mexican-American and five were White. In these interviews secondary data were collected on their insights (self-reported) when interacting with older Black women in healthcare encounters and to collect background perspectives on gaps in health education, delivery of health care, health status and health behavior among the local African American population. As secondary data, these unstructured interviews were used to determine appropriate health-related questions to be utilized within the study among older Black women. All data were collected with the informed consent of the participants and had the continuous (2002–2005) approval of the institutional review board at the University of Arizona, Tucson Arizona.

Study Demographic Characteristics

Table 1 summarizes the overall demographic characteristics of the participants. The average age of the women was 55±3 years. Forty-nine participants (98%) had health insurance.

Quantitative Analysis of Demographic, Health Status and Health Behavior Data

Participants spanned all income groupings, with most considered low to middle/high income status (data not shown). Socioeconomic status (SES) and racial positioning in the US may impact opportunities for education, employment and the ability to acquire/afford and maintain health insurance, thus having a "key" source of income is a factor. Analysis of "key income person" data collected among older Black women (n=50) indicated that slightly less than half of these women were the sole providers for their households. A similar number of these women had multiple sources of income, with income derived from part-time employment, spouses or live-in partners, or extended kin. A smaller percentage of the women received assistance from adult children not living in the household in addition to retirement funds. Three of fifty women declined to respond to the "key income" query, stating it "was nobody's business."

Quantitative data was collected on health behavior during the two years of the study with respect to preventive screening (mammograms and pap exams). Almost all (98% and 92%, respectively), had had mammograms and/or pap screening exams within the past two years. Almost all the older Black women in this study were compliant and less than five having been referred for further testing.

Qualitative Analysis of Cues to Ethnocultural Differences and Race

Analysis and interpretation of this qualitative data rested on established criteria for ethnographic research suggested in the work of Lincoln & Guba (2000) for assessing qualitative data to ensure that the rigors of reliability, validity and repeatability are met, particularly when "trustworthiness" is a concern for researchers. Hence, decisions made about analysis had to include those specific criteria (credibility, transferability, confirmability and dependability) [5]. The strengths of this ethnography are reflected in my reporting of ethnographic findings collected from data that references (as cues to behavior) the separate realities, constructed among a diverse population of older Black women, that influenced many of their expectations, perceptions, and experiences within healthcare encounters and the contexts in which these realities operate. Clearly, cues to ethnocultural differences and "race" are issues too complex to be measured by simple indicators of discrimination and racism when exploring the problems, behaviors, culture and contexts of older Black women's perceptions, expectations, beliefs and experiences within the US health care system. I expected that some abstractions would arise out of the data and would be discussed in the findings of my study. Such abstractions might be enigmatic, not easily transferable, and complex to non-Blacks, given that their levels of cultural competency for understanding sociocultural contexts of experiences, interpretations and histories of older Black women interacting within a (predominantly White) healthcare encounter might be limited due to unfamiliarity with having "race" as an identity. Consequently, the theoretical orientation for analysis and interpretation was built upon a framework of ecological theory, which seemed like a good fit for this particular ethnography.

Study Limitations

Important limitations include small sample size, which may not be representative of all Black women in this age group or in other US geographic regions. I did not attend clinics with participants, nor could I objectively determine the actual quality of healthcare encounters and provider-patient interactions. Thus the perspective of older Black women in my study are presented here in terms of their expectations and experiences with, and perceptions and beliefs regarding, patterns of practice in healthcare settings with respect to "race" and ethnocultural difference. The study's time frame (18 –24 months) was relatively short and therefore other non-clinical influences regarding health behavior may have been missed.

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[5] Lincoln Y.S., Guba E.G., 2000. Paradigmatic controversies, contradictions, and emerging confluences. *In* : N.K. Denzin & Y. S. Lincoln, eds. *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, (2nd ed): 163–188. I was able to address my concerns by implementing the following techniques suggested by Lincoln & Guba (2000): I used prolonged engagement, persistent observation through face-to-face interviews, triangulation during data collection and data analysis, peer debriefing , and finally member checks in which my working hypothesis were presented at a health-focused town hall meeting held in the local African American community. All participants were invited to attend. I provided thick descriptions , I compiled an audit trail , and finally kept a self -reflexive journal as the backbone for keeping a study record of observations about the research.

Results

I examined the data with regard to both sociocultural and ethnocultural states of being, in order to study in detail the perspectives shared by participants on the kinds of difference that constitute a "race," what differences "race" makes, and how those differences are determined within healthcare encounters. The interview transcripts were coded, categorized and analyzed using a standard relational database software program designed for the management, retrieval and analysis of qualitative data, ATLAS.ti.

The codebook I created focused on themes, categories, key metaphors, or terms that emerged when experiences, expectations and beliefs about "race" were related to healthcare encounters. As pertinent themes emerged and were repeatedly identified as being utilized to organize, frame, and share their experiences, these were coded as non-clinical influences and later grouped as ethnocultural differences, using the constructs of *healthy paranoias* and *ethnic notions* where appropriate.

Over one-half (52%) of the women in the study reported they had either been racially profiled or experienced racial bias in their most recent healthcare encounter, whether it was a screening exam or not. Such negative experiences certainly may have influenced whether the women returned to that healthcare provider/setting for follow-up. Nine (18%) women reported they were not sure if they had been profiled or discriminated against, indicating it was difficult to determine whether the behavior was due to racial bias or "lack of home training," e.g., generalized rude behavior. The remaining fifteen women (30%) said they had not experienced racial profiling, bias, or discrimination in their most recent healthcare encounter. Thus, in this small sample (n=50), 70% of participants felt or suspected that they had been racially profiled in their most recent healthcare encounter.

The Difference That Makes the Difference

Overview

Through the practices of discrimination, segregation, and prejudice, "individual values and behaviors [have been shaped] in ways that can enhance or impair health status" (Williams, 1996, p.1). Thus it can be proposed that individual patterns of health behavior among older Black women have been shaped and molded through their perceptions and experiences across a life course spent within a socially constructed racial identity that is ideologically sustained and objectively conditioned. Earlier I suggested that *healthy paranoias* and *ethnic notions* may represent factors used in constructing health-seeking behavior because older Black women have had time to choose from among a variety of ethnocultural factors as cues to action in terms of understanding themselves, negotiating their environments, and defining their experiences within healthcare settings. Several women in my study noted the practice of sharing and utilizing an ethnocultural fund of knowledge on risk, health history, hyper-vigilance and healthcare experiences, as well as perceptions and expectations that are part of their patterns of health behavior and individual practices of health advocacy. They described what I have called *healthy paranoias* and *ethnic notions* in relation to both individual and collective Black consciousness and culture, they theorized their potential to become powerful sources of energy serving progress and change, and they relished those transformative capacities for them and their communities.

Ethnographic Discoveries

Tables 2 and 3 illustrate many of the perspectives that were shared with me. These views were voiced multiple times throughout the study and transcended the original objectives and goals of this study. Particularly when narratives turned to discussions about "race" and "being" Black, and when recalling their own or others' subjective experiences, the perceptions, expectations, and beliefs of these women referenced any healthcare encounter/setting, not just those for screening exams.

I have highlighted the narratives of twelve women from my study, using pseudonyms to ensure their anonymity, in accordance with human subject guidelines. These women were particularly articulate and their experiences reinforce the stories told by other participants with respect to perceptions, expectations and beliefs about the health care system. Their narratives offer both insight into and interpretation of the contexts in which strategies impacting health behavior are constructed and reinforced and make it clear that if effective healthcare service, access, and utilization are to be encouraged among older Black women, an informed understanding of *ethnic notions*, *healthy paranoias*, and the role of ethnocultural differences is essential.

Participants easily discussed four levels of perceptions and experiences regarding their healthcare/clinical encounters: (1) how they knew they were being treated differently; (2) expectations and experiences of receiving less optimal treatment than Whites; and (3) interactions within healthcare settings, including *feeling uncared* for by providers and support staff and how these are shared within the Black community (Table 2a,b,c). Finally, participants reported misunderstandings and misinterpretations, including cues to behavior (Table 3).

Healthcare providers can build or destroy trust in a variety of ways, in which interethnic interactions play key roles. Since trust may mean different things to an older Black woman than to some other patients, misinterpreting ethnocultural differences may reify existing skepticism long before either actor has a chance to establish any credibility with the other, as shown in the comments from Table 2a.

Many women in my study felt the choice of words or phrases used by providers in sharing information was evidence of them being "treated differently" than White women, particularly when providers attempted to discuss health risks for specific illnesses. For example, Ms. Carlotta's (2003) comment in table 2a illustrates a gap in cultural knowledge that may distort a Black woman's perceptions of what went on in a doctor's office and impact her willingness to accept a doctor's advice, thereby reinforcing *ethnic notions* of "racial" differences. The expression "you people," when used by a White person in talking to or about Blacks , is a derogatory signifier. Thus, during healthcare encounters, neither the healthcare provider nor the older Black woman may be able to recognize that perceived "racial" differences are actually ethnocultural in nature.

In my study, women discussed "being" Black women as a factor in expectations that they would receive less than optimal care (see Table 2b). Women like Ms. Gladys in Table 2b may have felt the need to maintain a *healthy paranoia*, particularly in (predominantly White) healthcare settings, because of observations of Blacks being treated differently. Such negative experiences certainly may have influenced whether these older Black women returned to that healthcare provider/setting for follow-up and whether they complied with recommendations that were made to them.

Black women have learned, not only from their own experience but also from those of others, how to act to protect themselves from many possible racialized occurrences. Such hyper-vigilant perspectives need to be recognized by healthcare providers as a type of self-promoting health behavior, as these *healthy paranoias* may affect how well Black women respond within healthcare/clinical encounters.

The narratives in Table 2c refer to the quintessential power of having an ethnocultural fund of knowledge to use in patterning their own individual health behavior. Several women noted this construct as vital to their health and well being, as it references health risks, health histories, the need for hyper-vigilance, and actual healthcare experiences. These dialogues included "what other women said they did in seeking out healthcare," " what was expected to happen in that healthcare encounter," and "how each woman perceived or heard what actually did happen" in order to guide the intensity and quality of care she could anticipate receiving within a specific healthcare encounter, as illustrated in Ms. Renee's comment on an *ethnic notion*. *Ethnic notions and healthy paranoias* also seemed to draw from a steady diet of perceptions, expectations, and beliefs of <u>both</u> healthcare providers <u>and</u> older Black women that led to misunderstandings of intentions (see Table 3).

The significance of *context-in-interpretation* is a distinguishing feature of the healthcare encounters shared in Table 3. As noted by Ms. Brenda and Ms. Juanita's reactions, the type of racial cues understood within healthcare encounters may depend on which "racial" stereotypes are being triggered. Many stereotypes are so deeply embedded in Black / White consciousness that even those individuals who employ relatively low levels of stereotyping may have difficulty in recognizing the roles such stereotypes play in their everyday interactions.

As part of an ethos within the larger African American culture that also influences health behavior, *ethnic notions* and *healthy paranoias* become part of the matrix of collective social re-memory among some older Black women, a matrix that reflects experiences with, expectations of, and responses to racial bias. The interethnic experiences that occur over the life course of an older Black woman and/or a healthcare provider must also be understood as being constructed from *ethnic notions* about racial difference as cues to behavior. However, these cues may influence the perceptions and expectations of <u>both</u> healthcare providers and older Black women. As Table 3 illustrates, healthcare settings are often construction sites where expectations, perceptions, and beliefs take on lives of their own, as face-to-face interactions within these settings —between women, healthcare providers, and support staff— evolve into cues to behavior that support misunderstandings. Thus, these factors need to be recognized as critical elements in the delivery and receipt of the best possible care.

Discussion

In this study, *ethnic notions* and *healthy paranoias* emerged as appropriate vehicles for exploring perspectives shared among some older Black women in the US, such as their understanding of "race" and culture, as an integrated system of orientations and a repertoire of ideas and possible actions (Hecht et al, 1993). Older (US) Black women choose from among a variety of ethnocultural factors in understanding themselves, their environment, and their healthcare encounters. For example, some women expected that the health care system would actually be detrimental to Blacks; others noted that they had perceived or experienced bias through non-verbal cues such as a lack of eye contact, a lack or hesitation of physical touch, "facial movements, twitches and lip curls," or through actual speech, such as the tone or speed of voice or the type of language used. The women I interviewed also shared their insights on healthcare providers and support staff in healthcare settings who seemed to routinely express a belief that "being" Black meant that specific medical conditions could not occur nor could Blacks afford to pay for treatment or care if and when these conditions did occur. These experiences left study participants feeling uncared for by both providers and support staff.

Racial claims, truths, beliefs, and stereotypes have been developed, established and sustained in the US, and thus "race" has been made into a difference. The traditional conception of "race" rests on the false premise that natural distinctions are grounded in significant biological and behavioral differences, which can be observed between groups. While generally noting that healthcare providers did not seem to engage in intentional or overt racial bias when it came to African Americans and healthcare delivery, the (US) Institute of Medicine in 2002 nevertheless stated that even "well-meaning" racism manages to demonstrate and convey negative racial attitudes that harm health. Furthermore, the report did find clear evidence that the decisions made by healthcare providers on who got what kind of care were often based on personal perceptions and preconceived racial stereotypes about Blacks, despite the income, insurance status, or education of that Black patient. By the same token, an older Black woman operating on those assumptions that have been shared by a healthcare provider may in turn *racialize* a health encounter rather than explore her individual health history or patterns of health behavior, such as nutrition and exercise. Thus the shaping of a health inequity (disparity) begins.

Hence, it seems reasonable to assume that American Whites and Blacks have gone through very different socialization processes with respect to "race." It is possible that each group has constructed *ethnic notions* about the other and neither may be aware that their *ethnic notions* and *healthy paranoias* may lead to misinterpretations and misunderstandings in establishing respectful partnerships for optimal care. Further, there have probably been few chances for either party to unlearn inherited/shared perceptions, expectations, and biases, or to learn culturally responsive ways of interacting with each other.

Strengths and Implications

The major strengths of this ethnography lie in the shared points of view expressed by older (US) Black women who were diverse in their ages and circumstances. Clearly, participants viewed healthcare encounters as social transactions of ethnocultural difference. The characteristics of these encounters may influence providers' decisions on patterns of care, such as referrals, treatment options, and diagnostic tests, and may also impact individual patterns of health behavior among older American Black women, such as compliance, self-care, and decision making. If intervention approaches are patient-centered, then the values, beliefs, and experiences of the group are included in outreach efforts, and the capacity building of both patients and providers is enhanced.

Ethnocultural differences in relation to access and utilization of healthcare and to the delivery of optimal healthcare need to be explored in many local settings by examining the cues to behavior that are grounded in misconceptions. With many US Blacks already alienated from the health care system, it is important for healthcare providers "not to ridicule but to pay attention to" all of these factors, because together these elements may contribute to misinterpretations and misunderstandings (LaVeist 2002).

At the global level we must commit to designing transformational research for implementing ethnoculturally responsive models of patient-centered health interventions translational (Agency for Healthcare Research and Quality [AHRQ] 2007). These include understanding the contextual repertoires of history, language, and culture of all the racial/ethnic individuals and communities before us. Such models would encourage acceptance, integration of enhanced interethnic communication skills, and awareness of routines within healthcare settings; they would also mediate mistrust and increase patient and provider knowledge about the significance of an individual’s ethnocultural ethos in healthcare encounters, health interventions, service delivery, and follow-up.

Hence, we must develop new approaches to enhance our understanding of *ethnic notions* and respect *healthy paranoias* as items of relative importance to culture and the racial categorization systems used around the world. These systems have produced health inequities, both within and among countries. Therefore, the *science* for eliminating health disparities must include targeted research and implementation for disease prevention and for health education, promotion, and intervention that are cognizant of and responsive to ethnocultural factors, since effective and safe changes in health behavior can complement a community’s traditions, values, and worldview. These factors often determine how and when individual community members decide to use available health care. Otherwise, "we run the risk of attributing the behavior to individual shortcomings" rather than to the systemic agency of racial bias and of ignoring ethnocultural "differences that make the difference" and that could be critical to the health and well-being of the very populations that we seek to serve (LaVeist 2002).

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Table 1

Demographic Characteristics of African-American Women in Study Sample

		Number (%)
Age (years)		
	40–49	15 (30%)
	50–69	32 (66%)
	70+	3 (6%)
Education		
	High School Diploma / GED	13 (26%)
	Associates Degree , Technical Training, or Some College	22 (44%)
	Four-Year College Degree or Beyond	15 (30%)
Employment		
	Employed / Self- Employed	32 (64%)
	Retired with a New Career	10 (20%)
	Retired and not Employed	8 (16%)
Health Status		
	Excellent	26 (52%)
	Good	15 (30%)
	Fair	9 (18%)
	Poor	0

Table 2

Ethnographic Insights from Study Interviews

a. How they knew that they or other Blacks were being treated differently
…I do think that Black women are being treated differently… when you walk into the waiting room, and you're stereotyped… I've seen it; I've felt it. Other people come in and they are treated ahead of you, you know… when you walk into the office, and you say to them, "Could you get me in to see the doctor?" And they say "No, we cannot see you till next week." Then you have somebody else, a White woman, comes in right behind you and he or she says "Oh, just wait over there, and I’ll see if the doctor can see you." Colette, it's the privileging of them over me that also makes a difference (Ms. Satori 2004).
…Now that I think about it, even trying to get an appointment through the office staff to get in to see the doctors, I think that African Americans are treated differently. In terms of what I've observed,… [Blacks] go to the doctors and providers and they're just not treated the same .That's how I know, if I see and hear something different… that's how we all know(Ms. Catherine 2003).
…There's a condescending tone when they talk to you, whether they are male or a female, if they are White, and that’s usually the experience from the time that you walk in the door… I know you should have a good rapport with your physician, but …maybe he was focusing on it being a health issue for us, Black women, when he said " you people," but it was the way he phrased it that it did not come across that way. Me, I just leave (Ms. Carlotta 2003).
b. Expectations and experiences of receiving less optimal treatment than Whites
I can tell you that almost everyone I know has had some kind of negative clinic or hospital experience, where you’ve had to go in and fight for care or fight for service. I think for a certain amount of Black people that's one of the reasons they don't go, because they don't feel like they're going to be treated the same as Whites (Ms. Wiletta 2003).
To this day I still have a space there [in her gums] where I should have a tooth… because I was a little Black student, a little Black child with a check [a cash allotment for her dental work] It was a quick fix for him [the White dentist]. It was easier to take the money than treat me several times. I think that one experience really set it off for me because I didn't realize until years later how his pulling that tooth affected the rest of my teeth (Ms. Darla 2003).
We Black women feel so vulnerable, and were so taken advantage of in the past,… Women like myself, I know what happened. I am the older generation. They [healthcare providers and staff] need to understand what an African American woman of a particular age group might be going through or has gone through…it's a big thing in terms of trust. I have been labeled high risk for breast cancer so to be on the safe side I get my mammogram, but I' m not quite sure I trust them (Ms. Gladys 2003).
c. How interactions within healthcare encounters/settings are shared in the Black community
Black people have lost confidence in the healthcare services…We do work together. We will tell if we have been mistreated…and we do have community and we do support one another. When you mistreat or disrespect one of us, you cannot clean that up by going over and being nice to the next person…’cause we talk to each other…(Ms. Sharon 2002).
Someone goes to the [White] hospital and dies and then a lot of information is built up and shared among us about that death, which is not necessarily based on fact. We [Blacks] also don’t ask a lot of questions, we don’t stay on top of what's going on sometimes, and we just go on what's being said (Ms. Renee 2004).
I was told about a group of Black women from someone who knows that they were at King's County hospital clinic and they had pap smears done, and the women didn’t hear from the doctor so they thought that they were okay. But years later, it was found that these pap smears were still in the refrigerator and were never analyzed and some of these women had died of cancer. So that taught me to never wait on them [healthcare providers] and to call and call till I get my results (Ms. Irene 2003).

Table 3

Misunderstandings in healthcare settings and cues to behavior

I think it's how we describe what's happening with us and maybe they don’t understand our descriptions. …I think each different culture has way of conveying what's going on with their body. I think I scared a doctor one time. I use my hands a lot when I talk…I don’t know if I intimidated him or what because he backed up and hit his head - BAM-on the wall …I don't know what else could have made him react like that except that he thought I was an angry Black woman and that I was going to hit him…So it's sort of like they [healthcare providers] misinterpreted it (Ms. Juanita 2003).
They want you to take your clothes off, right away. We're still are not comfortable with exposing ourselves to them. It’s a cultural issue. Like if you're a White woman, you probably don’t care if parts of your body are shown. It's not an issue for you. But if you're a Black woman, you are much more concerned with being covered up. Even though they try to paint us as having early [sexual] experiences, as young girls,no, we do not (Ms. Brenda 2004).
There are a few Black nurses, a few Black doctors. But when you go in [to a predominantly White healthcare setting] you're trying to tell somebody about you and your health that has absolutely no frame of reference, absolutely no clue about the Black experience or your history. They probably have never even seen a Black person….so for us it doesn’t make it important to go get checked out because of how we are treated(Ms. Deborah 2002).