Abstract

There are many myths and stereotypes related to the health of people of color in the United States. Many research studies are done and statistics proliferate on the health status of non-dominant groups. Few studies attempt to understand the meaning systems of poor and working class African American women in relationship to health and health care. This study uses an ethnographic approach including narrative analysis of life history interviews in order to examine how the life experiences and belief systems of a small group of poor and working class African American women from a storefront church in Seattle, Washington, inform and influence the women's opinions and interactions with the dominant white health care system. This paper will examine specific dimensions of the women's belief systems and discuss how these beliefs are applied as the women interpret, confront and examine the meaning of health and the meaning of their own experiences in specific health care encounters. The women’s belief systems, learned and reinforced within the context of their daily lives, enable the women to offer a unique critique of the health care system, as well as to maintain a powerful subjectivity in the face of an objectifying system, the dominant white western health care system.

Keywords: African American; Health; Racism; Narrative analysis; Feminism; Resistance

Introduction

There are many myths and stereotypes that relate to the health of people of color in the United States. Statistics proliferate on the poor health of non-dominant races on innumerable parameters. News articles in the popular press are written daily, discussing and speculating on the reasons for the poor health of African Americans, Native Americans, and Asian refugee groups, etc. Most of these articles cite scientific research as the basis for the discussions. Health professionals are typically trained to utilize research which presents race as an influential factor related to health problems. However, according to Cooper and David (1986) “the uncritical use of the traditional biological concept of race” has created multiple problems in the health care arena. The authors state that such use of information “has distorted etiological thinking in public health and has proven an obstacle in the development of effective intervention strategies” (p. 97). The United States Institute of Medicine has recently advised scientists to “abandon traditional racial categories because they are ‘of limited utility for the purpose of health research’” (as cited in Schmid, 1999, p. A4). The Institute notes that the “concept of race rests on the unfounded assumption that there are fundamental biological differences among racial groups” (Ibid), and suggests that data could be more useful if collected on more specific ethnic or regional groups which would allow researchers to examine such variables as the impact of communities on health.

However, the racial categorization of health pro-
problems is deeply entrenched in the societal and professional consciousness and in the discourse of health in Western society. Health professionals and researchers are taught by other professionals who utilize this traditional approach to race in statistical information, and then inevitably incorporate this same approach in the education of clinicians. The educators of health professionals simultaneously integrate this information with their own clinical experiences, bringing their own personal histories, fears and stereotypes into their teaching and caregiving activities and into the clinical judgments that they make about their clients. Some fairly straightforward examples of clinical beliefs about African Americans that have become commonly accepted as true, are that they are at high risk for hypertension, that they have an unusually high infant mortality rate, and that poverty and lifestyle predispose many African Americans to a wide variety of serious health problems. Clinicians typically, having been exposed to this information over and over again, accept these beliefs as innocuous 'facts' without critically examining the repercussions of the relationship of the use of race as it corresponds to physiological problems and as the two terms are used as parallel indicators of poor health status.

Schiller (1992) notes that “instead of accepting that the concept of risk group is ‘useful,’ we must ask ‘useful for whom to do what?’” (p. 249). She points out that epidemiology constructs “a sense of citizenship, as those who belong to the strong and healthy general population of the nation are distinguished from the weak and vulnerable subjects of study … the ‘at risk’” (Ibid).

Analysis of the negative ramifications of categorizing groups in the AIDS crisis has been particularly illuminating in understanding the problems inherent in categorizations of certain groups of people (Crawford, 1994; Schiller, 1992; Singer, 1998; Sobo, 1993). Schiller (1992) found in her study of “at risk” groups and AIDS, that the construction of AIDS risk groups as culturally distinct served to compound the AIDS crisis in the following ways: by leading to misunderstandings about who is at risk and who is not; by creating poor targeting of health education attempts; by contributing to the spread of the disease because of confusion about who is ‘at risk’; by stigmatizing and marginalizing people with AIDS; by concentrating on the disease itself without noting that the disease is proliferating under the conditions “of unemployment and growing structurally caused poverty, the subsequent development of the informal economy of drugs, the lack of primary and preventive health care, the oppression of women and people of color” (p. 246). Schiller stresses that “the concept of risk group … has perpetuated these consequences through what it does not allow us to see as much as through the type of thinking it promotes” (Ibid). Sobo’s (1993) study gives a graphic example of how ‘risk’ categorizations can backfire in the public health arena. In the face of negative labels, HIV/AIDS risk denial has become “part of a self-protective strategy adopted in the face of racist finger-pointing and blame-laying” (p. 462). She notes that sexism, racism and other oppressions create forces on people’s beliefs about HIV/AIDS risks and on their perceived power to address risks that, in reality, are enmeshed in social, cultural and economic problems.

In order to examine more deeply why the statistical use of race as a dimension of health is problematic, we turn to the social sciences for discussions on how race is used in Western society. Rothenberg (1990) points out that “the construction of difference is essential to racism, sexism, and other forms of oppression” (p. 42). She notes that claims about difference “are offered under the guise of value-free descriptions yet smuggle in normative considerations that carry with them the stigma of inferiority” (p. 43). Rothenberg discusses how ‘difference’ in race, as well as in gender, as defined by nature/biology “performs certain critical functions” (p. 45). These are as follows: first, this difference implies a natural hierarchy, i.e. it is the natural order of things to have a superior and inferior group; second, since it is the natural order, those in power are absolved from responsibility for the condition of the inferior group and thus the victim is blamed for his/her own victimization; and third, since the difference is seen as ‘one of kind not degree,’ relationships are difficult to alter and significant change is unachievable.

According to Harding (1986), racial categorizations and comparison projects demonstrate many of the problems inherent in US society as a whole. She notes that categorizations which divide groups into white and ‘other’ (choose any race or ethnic group) show residues of colonialism, i.e. they speak to the development of a ‘universal other’ for purposes of domination and exploitation; they assume that people are without history prior to their relationships with whites; and they assume more commonality among like groups and more differences between unlike groups than may actually exist.

Crawford’s (1984, 1994, 1998) work demonstrates how societal beliefs about who becomes ill and who remains healthy, compound and intensify the ability of one group (in his research, the middle class) to create “an external other, people and groups that are negatively stereotyped” (Crawford 1994, p. 1355). In his research, Crawford (1984) found that the language of health is commonly used as a metaphor for “self-control, self discipline, self denial and will power … concepts that are fundamental to the Western system of values” (p. 77). In Western society, “the healthy body is the property of a deserving owner” (Crawford, 1994, p. 1356). Health has come to be “something that could
be achieved ... a social idea ... an essential foundation of character ...” (Ibid, p. 1349). Just as health has come to be seen as a characteristic that is justly deserved by the person who performs all the correct behaviors (as advised by the barrage of health promotion efforts), ill health has come to be seen as being justified as well. Disease is related to a person’s “inability to care for himself with ‘healthy behaviors’”; and illness appears to be tied to “a fatal flaw of character or a personality defect, in an unconscious predisposition toward illness, or in living ‘a high stress’ life with poor ‘stress management’...” (Ibid, p. 1356). Crawford (1994) emphasizes that, in this consciousness about health, there is “a social distancing from the ‘unhealthy,’ a further stereotyping of already stigmatized groups who then, because of their ‘irresponsible’ habits are confirmed in their Otherness” (p. 1356). Crawford points out that,

the statistical basis of attributes that connect particular diseases to certain groups and behaviors only gives an appearance that rational influences are at work. The connections, however, often resonate with deeply ingrained, implicit meanings and powerful moral judgments. The sick are made not only responsible for their illness, they are also made different (p. 1356).

He demonstrates how, since the nineteenth century,

the language of health [has come] to signify those ... who were responsible from those who were not, those who were respectable from those who were disreputable, those who were safe from those who were dangerous, and ultimately, those who had the right to rule from those who needed supervision, guidance, reform or incarceration (p. 1349).

Crawford (1994) notes that “in a risk conscious era, the ‘healthy’ self develops an even greater investment in the delineation of boundaries” In short, “self needs other”. As social distance between groups widens, “attributions of self-destructive disregard and irresponsibility also increase”. These beliefs are often deeply enmeshed in ideas of “victimization from a destructive social and physical environment” and this only serves to magnify judgments, thus “[converging] with other victim blaming ideas about the poor and the marginalized”. As such, ‘high risk’ is a label given to individuals “who, unlike the privileged, are ‘locked’ into ‘cycles’ of deviance and self destruction ... The otherness of the sick or the high risk individual ... is, in short, a boundary maintaining device that serves multiple agendas” (pp. 1357–1359).

There have been profound consequences historically to the classification of people into categories related to race, class or gender in the health care arena. The Tuskegee Syphilis Study where 399 black men from Macon County, Alabama were denied treatment for syphilis in order to study the course of the disease, is perhaps the most well known project that treated a group of people as ‘other.’ As Gamble (1997) states, this experiment “has come to symbolize racism in medicine, misconduct in human research, the arrogance of physicians, and government abuse of black people” (p. 1773).

Gamble (1997) demonstrates that this situation is not an isolated event, rather it must be placed within its broader social and historical context. She specifies that this experiment reflects a historical pattern of dehumanization of black people by the medical establishment. Black peoples’ fears and feelings of distrust, even today, are based on an extensive history of experimentation, on receiving the worst care from student doctors in the poorest segregated wards, on the stories of black bodies being stolen from graveyards by ‘night doctors’ for study, and on fears of deliberate genocide from exposure to syphilis, to AIDS, and to drugs within black communities. Sobo (1993) found that, “in discussing the origins of AIDS, many black women reported having heard talk of laboratory accidents, contaminated water, or information that was being withheld ... men spoke openly of AIDS as a part of a racist plot to eliminate blacks” (p. 466). Sobo (1994) notes that

the experience of racism and the legacy of the negative encounters that African Americans have had with the public health system, as well as the mistreatment that women and the poor historically received from the biomedical sector fuel the misgivings that many African American women have about health care workers’ motives and interests (p. 21).

Gamble (1997) points out that “the powerful legacy of the Tuskegee Syphilis Study endures, in part, because the racism and disrespect for black lives that it entailed, mirrors black peoples’ contemporary experiences with the medical profession” (p. 1776).

Young (1982) discusses how “many medical practices develop and persist because they are useful for other people and for reasons unconnected with curing and healing” (p. 271). Taussig (1987) points out that social problems and health care are intimately interrelated. He states that the health sciences can be used for “political goals in a large number of complicated and interacting ways” (p. 19). He discusses how health care often “takes the political edge off some of the outstanding social problems that the system as a whole produces, without necessitating deep changes in the system itself, [noting that] medicine is a specifically pri-
viled tool in that its humanitarian image allows for the penetration of forces that might otherwise be unacceptable” (p. 19). It is important to understand how health care research and its subsequent discourse, i.e. ways of presenting information, can both reflect and determine overall societal attitudes and values toward a group of people, as well as predispose this same group to receiving a particular type of care in the health care system. West (1995) notes that race does matter in the health care discourse, but not necessarily for health reasons. Rather, race matters because categorizations present black people (and other non-dominant races) as ‘problem people.’ Health care funds are directed at this or that ‘problem’ of poor African Americans without ever questioning “[what] this way of viewing black people reveals about us as a nation” (p. 557) or more specifically, what this view reveals about the US health care system.

In order to adequately address issues of oppression in health care, Baer, Singer and Johnsen (1986) call for “the dialectical examination of contending forces in and out of the health arena that impinge on health and healing” (p. 95). They stress that, in analyzing health and health care, the questions of power must be addressed on several levels — the macro-social level (health agencies, multinational drug firms, agribusiness), the intermediate level (health administration), the micro-social level(doctor/patient interaction), and the individual level(patient’s support, his experiential response to illness). Singer and Baer (1995) note that it is essential for critical medical anthropology to “seek to understand the play of power, as exercised both during (in the immediate structuring of provider-patient relations) and through the interaction (in the reinforcement of existing class, gender, or racial relations)” (p. 73). These authors see that the US medical system is a “reflection of class, racial/ethnic and gender relations in the larger society … [it] constitutes an arena of struggle among these social divisions” (p. 182). They note that “whole worlds come together in the clinical encounter” (p. 73); and that, inevitably, through the doctor-patient “encounter and the expression given thereby to underlying contradictions, medicine is established as both an arena of social conflict and a structure of social control” (p. 34).

Taussig (1980) develops this idea, pointing out that in the western biomedical model of health care, the clinician–patient relationship has become reified into diagnosis and treatment, and behind this screen lies a social relationship of control that supports the dominant order. There is a false illusion of reciprocity in the clinician–patient relationship and the patient receives the message: “Do not trust your senses, but leave the facts of physical matter to the doctor’s control” (p. 9). The patient becomes both subject and object and the term ‘health care provider’ has come to mean ‘one who provides health,’ i.e. one who has the power to give health. Hidden behind this term and behind the reification of the clinician–patient relationship are issues of control, of helping the patient ‘to comply for his/her own good.’ Taussig states, “It is a strange ‘alliance’ in which one party avails itself of the other’s private understandings in order to manipulate them all the more successfully” (p. 12).

Scheper-Hughes and Lock’s (1987) work on the ‘three bodies’ provides partial insight into this issue of social/medical/scientific control as an objectifying process in western medicine. These authors see that there are three bodies: the mindful body; the social body and the body politic. The medicalization of the body misses the connections between the individual, the phenomenological self and the social, instead transforming the social into the biological. Scheper-Hughes and Lock find that the body is a symbol, a convenient means of justifying particular social values, and social arrangements such as the ‘natural’ dominance of males over females or perhaps the ‘natural’ predisposition of certain races to have physical problems, such as hypertension.

Under the auspices of the body politic, societies reproduce the ‘correct’ body, or individual for the particular time. For example, the ‘correct’ body for a people under threat has historically been a strong, aggressive warlike individual. In today’s dominant society the politically correct body is ‘lean, strong, androgynous and physically fit’ (Scheper-Hughes and Lock, 1987, p. 25). The authors see, like Crawford (1984, 1994), that health has come to be seen as deserved. They state, “Health is viewed as an achieved rather than an ascribed status … Ill health is no longer viewed as … a mere quirk of nature, but rather is attributed to the individual’s failure to live right, to eat well, to exercise …” (Scheper-Hughes and Lock, 1987, p. 25). Proliferation of disease categories and labels contribute to this view by labeling who is ‘normal,’ thus creating ‘a sick and deviant majority’ (Ibid). Scheper-Hughes and Lock believe that individuals are mostly unaware of these forces that control them. It is only during times of intense emotion, such as in sickness or in moments of deep trance or sexual transport that the “mind and body, self and other become one” (p. 29).

Comaroff (1985) describes how individuals can be both knowing and unknowing about the process of being formed and/or influenced by the political and social forces surrounding them. She discusses how persons who have been decentered by forces beyond their control attempt to “reconstruct themselves and their universe” (p. 3). She sees that resistance to controlling forces is demonstrated through “novel symbolic orders” that come into existence (p. 119).

Taussig, Scheper-Hughes and Lock and Comaroff
all portray the self primarily in its ‘unknowing’ state, created by social forces, with the self enacting its subjectivity through symbolic forms or during times of intense emotion. According to these authors, development and enactment of subjectivity is seen as mainly a reaction to the objectification processes.

However, it is important to stress that there are multiple dimensions in any interchange of power and social conflict. Singer and Baer (1995) note that socially constituted categories of meaning and the political-economic system are strong forces that shape the day-to-day realities of individual lives. However, they state that they do not mean “to imply that individuals are passive” (p. 101). Singer (1998) believes that it is critical to incorporate the macro-social level in any analysis, but it is also crucial to understand the relationship between “structure and agency” (p. 330).

It must be noted that theories that portray the development of subjectivity as a response to a dominant power support the notion that subjectivity develops from an objectification process, rather than as a creative endeavor. The feminists, such as Harding (1986) and Alcoff (1988) question this concept, bringing about a subtle shift in emphasis by seeing that experiences, rather than outside forces, are primary to an embodied self. Subjectivity (and the subsequent development of meaning for an individual) is thus formed by positionality within context. Throughout life an individual finds herself in many positions within many contexts. In short, she has many experiences. Not all are oppositional ones, not all are in response to a dominant order. In addition, these feminist theorists see that there is no subject/object split, and that so-called ‘objects’ are, in reality, active, not passive. Thus, individuals/subjects are constructed and construct themselves and their meaning systems through experience; that is, through active interchange with political, economic, social, cultural and historical processes with which they come in contact. Although these outside processes do have an influence on the experience of the individual, that experience is an active interchange, thus the individuals influence the world around them and they are actively involved in the creation, construction of their own ever-changing subjectivities.

Although science, and particularly biomedicine, has often tried to objectify women of color for its own purposes and for societal purposes, it has not been very successful in its project. Hence the same frustration is often heard or implied from health professionals: "If they would only do what we tell them to [choose one: they, their health, their babies, the society] would get better." This project of objectification has not belonged to women of color. It has been an outside project perpetuated by the dominant order and has failed to grab their attention, much less to control the women. Although it is important to acknowledge that the attempt to objectify women of color has been made and that some women do feel alienated from the system at times, they are not alienated from themselves. As the pastor of the church in this study says, “She knows who she is.”

It is certainly impossible to entirely escape the idea of ‘outside forces’ having an influence on the shaping of an individual and her beliefs, however, individual agency can be seen as at least as important as these forces. If academic theorists can recognize that we have all been formed, in part, by the structures of domination and power in our society, so can others. Within this recognition itself is a knowing subjectivity. As Pratt (1986) says, “Subjective experience is spoken from a middle position already within or down in the middle of things, looking and being looked at, talking and being talked at.”

According to Jaggar (as cited in Martin, 1987), there may even be a decided advantage to being on the margins when striving to understand systems of power. She states, “… many members of the ruling class are likely to be convinced by their own ideology … Oppressed groups, by contrast suffer directly from the system that oppresses them … Their pain provides them with a motivation for finding out what is wrong …”(p. 190).

Martin (1987) finds that the black working class women in her study, women who suffered from the “triple jeopardy of race, class and gender” seemed to come closer to achieving a critical stance about their health care than did women in other groups (p. 193). She states, “those at the bottom of the heap tend to see more deeply and clearly the nature of the oppressions exacted at the top of the heap” (p. 202).

A study of black Christian women

The relationship between the macro-social level, the intermediate level, the micro-social level and the individual level (Baer, Singer and Johnson 1986) in health and healing can only be fully understood by examining social forces, by understanding health care systems, by studying clinical encounters, by examining the day-to-day lived experiences of the people involved and by listening to the views of the people experiencing both oppression and creating agency in their world. This study seeks to understand the views and experiences of a group of poor and working class black women (the women self referred, choosing the term ‘black’) from a small storefront church. The women in this research study had clear views about the health care system which they shared with me during the eighteen months of my project. In casual conversations and in inter-
views, the women made frequent reference to the historical legacy of racism, to the racism they experienced daily in their health care encounters, and to the everyday management of the messages they received. Thus they readily moved back and forth between the micro and the macro social worlds that affected them every day, and they employed individual agency as a counterforce. As Young (1982) states, ‘informants’ statements seem complex . . . because they often juxtapose different kinds of knowledge. A speaker does not necessarily know all of his facts in the same way, and he often gives different, epistemologically distinctive accounts of his sickness at the same time” (p. 272). As the women voiced their views, it was clear that they both created their own meaning and understood that this creation was influenced by the world around them.

This qualitative ethnographic research project was conducted with a group of black women, their families, and church leaders, who attended the Morning Sun Missionary Baptist Church (pseudonym), located in a residential area of the Central District in Seattle, Washington, US. There were 35 members in Morning Sun Church, and since this research was done with a very small church membership, its results cannot be generalized to other groups. Of these 35 church members, five of the women, (along with the pastor and his wife), did the majority of the work of the church. Two core intergenerational families, each with four generations in the church, made up the majority of the church membership. In addition, there were a few isolated elderly women whose children were “raised in the church” but who were now grown and gone. The families in the church had all originated in Louisiana or Georgia. Family members had come north during the Great Migration of the 1940’s, seeking opportunities, mostly with Boeing aircraft or with the shipyards in the booming World War II industries in the area. The women participating in the interview portion of the study ranged in age from 19 to 82. Their incomes varied — some were on welfare or disability; some were the ‘working poor’ (one had an annual take-home pay of around $9,000 which supported between four and nine family members, the number depending on the situation of grown children and their offspring); some were employed at ‘good’ jobs as bus drivers or as computer operators. One family, with both spouses working (the wife as a bus driver, the husband as a city disposal worker), made a combined income of $50,000. The women varied in their level of education. One elderly woman had finished the fourth grade, others had dropped out of high school. Still others had ‘some college’ and the pastor’s wife was one academic term short of attaining her master’s degree.

Methodology

Two research methodologies guided my research approach and process, traditional ethnographic participant-observation method and feminist methodology. This combined approach allowed for a rich generation of data that incorporated the following: my observations and the women’s views about day-to-day experiences with race, class and gender; their views and my observations on clinical encounters and health experiences; the women’s interpretations of their experiences with power and oppression; their views and mine on how their philosophies related to God and prayer functioned both as creative healing forces and as resistances to dominant ideology.

From the anthropological literature, I drew on concepts related to “thick description,” symbolism, and the incorporation of self reflection throughout every step of the research process. (Bowen, 1954; Comaroff, 1985; Geertz, 1973; Hurston, 1963[1935]; Martin, 1987; Meyerhoff, 1978; Rabinow, 1977; Pratt, 1986; Shostak, 1983). From feminist methodology, I utilized principles of feminist participatory research in designing and implementing the project. Moore (1988) states that feminist ethnography is “based on the multiple authorship of anthropological texts [and represents] both the interlocutory process of fieldwork and the collaboration between anthropologist and informant on which the practice of social anthropology rests” (p. 174). Kingman (1997) notes that feminist participatory research includes “a non-hierarchical . . . approach in which the context surrounding phenomena is acknowledged and studied and the impact of the researcher’s values and emotions on the research process is acknowledged” (p. 251). According to Thompson (1991), feminist participatory research is committed to a gender focus, is oriented toward the transformation of gender-power relations, and is committed to understanding a diverse range of women’s struggles and experiences within context. A model of feminist participatory research “requires that the researcher/s and the participants establish the focus, direction/s, process and product of the research together” (Thompson, 1991, p. 31).

A key issue in feminist participatory research is the establishment of a non-hierarchical relationship between researcher and participants. Although anthropologists have clearly dealt with power differentials in their work, I found that the feminist literature was helpful in clarifying the difficulties I faced in doing research as a white, well educated middle class woman studying with poor and working class African American women. I was realistically concerned that the power differential inherent in our relationship would influence every step of the research process and
I wanted to neutralize this as much as was humanly possible throughout the research study. Like Stack (1974) I believed that the question of ‘entry’ into the research setting was very important. Thus I chose to do this research about health in a church where the church members ‘held the cards’ rather than in a clinic or a school setting where the power rested in the dominant white values and ideology. I found that it was important to access the church hierarchy correctly. I first met with the church’s designated ‘missionary,’ a person who works with outsiders and teaches them about the church mission. Missionary Lake advised me to seek permission from the pastor to observe and participate in the church services. Pastor Kent sanctioned my work. However, neither he nor Missionary Lake granted permission to do interviews. Rather I was told, “We’ll see about that.” In reality, the members of the church needed to get to know me in order to trust me. It was only after I had participated at the church for fifteen months, and only after the women had been strongly encouraged by the pastor’s wife, that they agreed to share their life histories in an interview process.

Prior to initiating the interviews, I tried to be true to the principles of feminist participatory research in other ways, some of which were successful, some of which were not. For instance, although I asked two of the women leaders to help me design the research method and questions, they refused to do this, saying “You know what you want to find out, so just ask.” However, I found that ‘just asking’ was not that simple and I received minimal responses to my questions for a long time.

Communicating with the women seemed fraught with difficulties and it was only after much trial and error on my part that I learned that some of my most
innocuous (to me) questions held undertones of racist assumptions that were offensive. My most basic inaccurate assumption in casual conversations and in interviews, was that the women saw themselves as I had been trained to see them, and as they were presented in the popular and academic literature, as an ‘at risk’ vulnerable group. This assumption was, at best, puzzling to them, and at worst, it was insulting and racist. It became clear that my ‘subjectivity’ was influencing the presumed ‘objectivity’ of my research questions. In addition, it was apparent to me on a ‘feeling level’ that there were some issues of power and control at play and that the women were successfully resisting my questions. After an initial unsuccessful and tense ‘researcher-led’ interview with Missionary Lake, I recognized that my questions and the assumptions behind them were a problem, as was the interaction of one person questioning another about her life. Minister (1991) points out that, in the standard oral history frame,

topic selection determined by the interviewer questions, one person talking at a time, the narrator ‘taking the floor’ with referential language that keeps within the bonds of selected topics — denies women the communication form that supports the topics women value (p. 35).

Minister notes that women value same-sex equality, but this ‘interviewer-led’ style sets up an immediate hierarchy. Thus it becomes important to equalize power differential through one’s approach in the interview. I found that the following were important ‘equalizers’ in the interview process with this particular group of women: (1) the women took greater control of the interviews when we met in their homes versus a neutral setting or my home; (2) I incorporated the idea of ‘making meeting’ (Banks-Wallace and Saran, 1992) by always bringing a gift of food (sometimes lunch, but often fruit and cookies for impatient children); (3) I let the women determine how long the interview should take (anywhere from 2–6 h over a 1–2 day period); (4) I discarded all of my questions, seeing that the women’s stories could take me places where I wanted to go; (5) I held conversations with the women during the interview, i.e. I fostered dialogue by sharing my reactions, my beliefs and values, and my experiences; (6) I protected the women’s privacy by encouraging them to turn off the tape recorder at any time, by assuring them of anonymity (the women chose their own pseudonym — often the name of their mother or an idealized individual such as a gospel singer), and by giving them the opportunity to read and delete any portion of their life history before publication; (7) I followed the advice of Missionary Lake and the pastor’s wife that the women would be insulted if I offered to pay them for the interviews. Instead I offered them favors or small gifts in return for their time. (For example, I made a genogram for one large extended family, I helped one family without a car with transportation, I gave Christmas gifts to the children of one family with whom I had a close relationship, etc.).

In order to allow for the most open-ended type of interview possible, I adapted Minister’s (1991) feminist approach to interviewing and used an unstructured interview format to prevent myself from controlling topics. Each woman was asked, at the beginning of her interview, to tell the story of her life as if she were writing it. She was told that the story could begin and end at any point. Concepts such as ‘spirituality’, ‘death’, ‘how you manage’ and ‘feeling good’ were written on a single sheet of paper and were used to ‘trigger’ topics that the story teller might address in the course of the interview (see Fig. 1).

Life history interviews were conducted with nine of the women, seven of whom were from two of the ‘core’ church families. This intergenerational approach enabled me to interview three generations of women in each of the core families, providing fascinating familial, developmental, and historical perspectives to the experiences of large extended families. In addition, two elderly women, widows, living alone whose children were grown and gone were interviewed. All of these interviews were much more than simple narrations of life’s events. As the women described their experiences and the context of these experiences, they related their fears and beliefs about motherhood, death, racism, men, health, God, children, the public schools, work, and the dominant white social system that touched nearly every aspect of their lives.

During the 18 months that I studied at the church, in addition to the interviews, I collected traditional ethnographic information from a variety of experiences. I participated in Sunday services, went to social events, attended Bible study groups, and went with church members to ‘fellowship’ with other churches. I also spent time with the women and their families outside of church functions. I went to dinner with them and went shopping for clothes and groceries and Christmas trees. I visited with them in their homes and went with them to doctors’ appointments, to visit relatives in the hospital, and to sign their children up for school.

In analyzing the data, I incorporated feminist principles in that I began my analysis with the women’s life stories. Thus, I attempted to firmly ground myself in the reality of the women’s day-to-day experiences, interpretations, and context. I agreed with Cantarow’s (as cited in Scott, 1991) notion that “the people who have lived through particular events are the ones best qualified to talk about them” (p. 9). In writing the women’s stories I simply organized the stories into
with the dominant white society. The women organized the importance of various events, analyzed how particular incidents had changed the courses of their lives, and clearly described the meaning of interactions, both positive and negative with the dominant white society.

Once I had centered myself in the women’s stories, I began to analyze all of the data — including my own reactions to specific events. The incorporation of this self-reflective process was essential for me to understand my subjective influence on the interactions and on the analysis of the content. There were four principles that I held as I did every step of the analysis: (1) the pastor’s wife had often pointed out to me that “the simple is the most profound” and I tried to keep my analysis and my writing clear so that anybody who wanted to could read the study (Collins, 1990; hooks, 1981; Spradley, 1980); (2) since I have a tendency to see women, especially black women as victims, I tried to keep them firmly in mind as agents (as Mohanty (1984) points out, there is no universal oppression, only a universal struggle); (3) As I did the analysis, I continually asked the question “How” instead of “Why” (Hancock, 1989) to prevent myself from making judgments and to stay firmly centered in the women’s reality; (4) I acknowledged that whatever I wrote could be used for political purposes to either hurt or to help black women and so I attempted to examine my writing carefully from every angle to see if it would contribute to the liberation or the oppression of black women. (In the end I was not sure I could control how the reader would choose to use the information).

Only after I had thoroughly grounded myself in the women’s voices and in my own subjective biases, did I begin to search for themes throughout the data — consistent patterns in what the women said and did, words repeated over and over in sermons and music, in Sunday school, during social times, throughout the interviews, when we went shopping or for a ride in the car. Research data from these interviews, from casual conversations in the community and at church, as well as more formal material from sermons and songs during church services and Bible study was compiled, coded and arranged categorically in broad themes, then analyzed for subthemes. (I was confident in my decision to combine church-related data with the ‘everyday’ data and the information from the interviews, because the women’s everyday lives were closely enmeshed with their religious beliefs and practices. The women spent anywhere from two to twelve hours in church every week, they described themselves as praying several times a day, and they stated firmly that their beliefs in God and Jesus guided them in all aspects of their lives.)

There were several subthemes that emerged from the health-related data. These themes were as follows: (1) general beliefs or theories that helped the women to cope with life’s problems and challenges in general; (2) beliefs about the body and Who has power over healing the body; (3) experiences with health and feelings related to personal experiences in the health care system; (4) views about the discourse generated about black women in the health care macro-social system (specifically discourse related to statistical information); (5) descriptions of how the women responded to and took power in an often discriminatory and judgmental health care system when forced to seek care for themselves or their families. The remainder of this paper will discuss these subthemes related to the women’s beliefs and views on health, healing and the health care system.

The women’s theories

This section will begin by exploring some of the women’s belief systems that helped the women live their lives and deal with times of trouble, i.e. their ‘theories.’ The word ‘theory’ is deliberately used and is defined as follows: “an explanation based on thought; explanation based on observation and reasoning, especially one that has been tested and confirmed as a general principle explaining a large number of related facts.” (Barnhart and Barnhart, 1993). The women’s theories were, in fact, “explanations based on observations and reasoning” that had been “tested and confirmed,” not just historically, but by the women themselves in their everyday experiences.

One of the most central of the women’s theories, addressed over and over again by the church members and church leaders, was that there was a difference between education and intelligence. The pastor’s wife, spoke often of the false intellectualism that came with advanced degrees. She stated, “when we get a little academic training, we get ‘the big head,’ but we ain’t nothing without the Lord . . . you never get so academic that you don’t need the Lord.” She believed that “It is easier for the simple people to accept Jesus. If a mind is analytical, it’s a little hard to get through to.” She pointed out that the multitude was unwilling to believe in Jesus because he was a carpenter’s son and the people were focused on prestige — they were waiting for the son of a king. She stated “Some people think they know everything. They look down on people who may not be as well-learned, but the depths of things come from the unlearned.” It is important to
note that these comments were from a woman with an advanced degree who strongly valued education. The pastor’s wife always admonished the children to further their education, but added that they must “put God first.”

There were many traditional black sayings that addressed this same issue. A visiting preacher said, “up here will fool you (pointing to his head), in here will school you” (pointing to his heart). Another preacher quoted Rosetta Carr, “You can go to college, you can go to school. But if you haven’t got religion, you an educated fool.”

Collins (1990) described a similar concept in her work. She pointed out that life as a black woman required wisdom because it was essential for survival. Thus, black people were quick to ridicule ‘educated fools’ with ‘book learning’ but no ‘mother wit’ (p. 208). Concrete experience was the criterion for credibility: “personal experience is considered very good evidence. With us, distant statistics are certainly not as important as the actual experience of a sober person” (Nelson as cited in Collins, 1990). According to Collins, “ideas cannot be divorced from the individuals who create and share them” Every idea has an owner and that owner’s identity matters” (pp. 215, 218).

For the church members of Morning Sun, there was a very important concept which related the meaning of intelligence to the body and to healing. One had to understand that Jesus was in charge of the body. The pastor’s wife stated this eloquently, “He’s my mind, my feet, my hands. If He doesn’t let me do it, I can’t do nothing…”

“This belief system about the meaning of the body and its relationship to intelligence was explored more deeply in a sermon by the pastor on nature and the body. The pastor often utilized metaphors taken from nature, demonstrating the rural roots of the congregation whose original members had migrated from Southern farms and small towns. The pastor entreated his congregation to look to nature for the answers to their questions. He led them carefully in his sermon, first discussing the phenomena of all of nature, then applying these concepts as he spoke of the wonders of the body. He spoke with amazement of the mother hen who knew how to protect her “ten or twelve or fifteen little chicks” from the hawk. He marveled at the stripes on a watermelon saying, “I want you to take it and count the stripes…they say it’s even and to me, it looks like they have to be — stripes all around, don’t run out…Who make it that way? Can’t nobody make it like God …”. He laughed about the wisdom of the design — that God did not have melons growing in a tree, “it’d be dangerous”; but instead He put the tiny cherries in a tree and the melons on the ground where they could not hurt anybody. The pastor spoke in wonder about the flower that bloomed only at night — one could not see it, but it was the most fragrant flower so its beauty could be known. The pastor discussed how God made the elephant’s hind legs and forelegs to bend in the same direction — pointing out that otherwise the elephant could never raise up from the ground.

Only after the pastor had marveled at the beauty of nature, was he ready to talk about the meaning of the human body. He began by emphasizing that man was made in the image of God. He then described the wonders of the body, simply, graphically and with humor:

It would be terrible if our nose was turned the other way — it would rain in there! Look how God shapes us, how He makes us, looks out for us … To make people with ears so they could wear glasses! What if your ears wasn’t there? (laughter) Ain’t you glad you’re you!? Isn’t that love?…It’s a good thing God didn’t make our elbows up here (indicating his shoulders). Without elbows…our arms would just bend backwards and go all to pieces. He love us and give us five senses and that’s why He say “I would not have you be ignorant! I’m an intelligent God and I want you to be intelligent!” He wants you to be in His likeness…Touch all you fingers together. I can see you laugh, but…You couldn’t write, you couldn’t pick up a little pin…Can you see? Can you Hear? Can you walk?…God made you with hands, made you with a brain…If you don’t use it, you got no business with it!…

The ‘intelligent’ person recognized the most essential meaning of the body, that it was a beautiful gift from God, given so that one could know God. The intelligent person also held another truth, that only God had power over the body.

There were other core elements of the meaning system related to health and healing. No matter what happened to one in life, the members of Morning Sun Church encouraged one another to count their blessings. One member quoted her mother saying, “Child, don’t worry that you have no shoes because some people have no feet.” The pastor always wanted hair like his brother, but finally he realized that “I could have no head!” The pastor urged members who did not always have the right foods to think about people eating out of garbage cans.

The pastor tried to help members cope with illness by ascribing meaning to illness, saying, “Sometimes we bring it on ourselves, sometimes it’s hand down … be way back there in the family. Mighta been your mother’s side … Mighta been your father’s side …” He saw that sickness was sometimes related to sin. He
stated, “Sin causes us to be sick a lot of time. We may bring it on ourselves a lot of time.”

In addition to seeing that the individual could control aspects of illness related to sin, the pastor encouraged patience and hope when coping with illness or with other problems. He pointed out that “there’s waiting times” just as there were for Abraham. He tried to help his church members be philosophical about these times saying, “But when we done worry- ing, we in the same place.” He reminded them of how God told Job, “Look at the stars and the sun . . . if I did all these things, I can take care of your little problems.”

One of the most effective methods that the pastor used to inspire hope in his congregation was the repetition of simple but meaningful phrases (often taken from the Bible). The following are examples of these hopeful messages:

- Weeping comes in the night, but joy comes in the morning.
- After a long drive, you can see the lights of the city and know “I’m gonna make it now.”
- Trouble don’t last always.
- There’s a bright day somewhere and I can find it.
- Stand at the door and knock and it’ll open.

The pastor believed that the best action anyone could take when ill was to pray. He stressed his point, using a medical metaphor, by saying that “when you got problems . . . what you need to do is ‘Operation Pray.’” He noted that often “We’ll try everything else and then we’ll try Jesus last.” The members of Morning Sun learned to pray in a particular way. They asked God to grant their request, but added “if it be Your will,” or prayed the words, “Fix and change as You see fit.” They believed that they did not have the comprehension that God did, and thus could not know all of the circumstances. In their experience they had sometimes received what they had asked for, but the situation had not turned out the way they had hoped. Thus they had learned to acknowledge their limited power and experience; and in the end, they turned it over to God.

If prayer was seen as a healing force, then, according to the pastor, the purpose of the church was “to be a hospital to all kinda people.” The church “should be a place where someone in distress can come,” and “it rescues us from the forces that hurt us.” The church was a “place people come to be revived . . . when the Spirit comes in sometimes, it speaks to the individual and takes away their problems.” As members became more and more “like Him,” they left behind physical ailments — at least for a time. One woman said, “If you feeling bad and you in church and you get in the Spirit, at least them couple of hours of church . . . When you walk out the door, that pain might hit you again, but when you sitting there, you feeling good.”

Often during a particularly moving sermon, one of the women exclaimed aloud, “Medicine! Medicine!” acknowledging the healing power of the Word.

Baer (1981) notes that these views of illness and healing stress the importance of the individual and of certain magical-religious rituals. These aspects of a religious faith offer important coping mechanisms, but simultaneously imply that the blame for the illness lies with the individual, ignoring societal influences. The ‘medicine’ of the church and the Holy Spirit offer a healing therapy which acts as a palliative for the individual and discourages him from seeking social change. These approaches, according to Singer and Baer (1995) “tend to be compensatory and accommodative rather than corrective” (p. 295). However, church members interpret the influence of prayer and the healing power of the Spirit in a different way. They would agree that “the Spirit” heals the individual, but they would not deny that societal change is also necessary. However, they see that the most powerful tools for societal change lie in prayer and in the power of the Holy Spirit. Their most well-educated member, the pastor’s wife, who was often their spokesperson, reacted indignantly when it was pointed out that some people believed that religion could lull people into an acceptance of the status quo. She stated vehemently that Jesus had changed the world more than any other person and that the church members followed his teachings. The pastor discussed this belief often saying, “Christ is love and love is the answer. It changes things!” The church members and the pastor often repeated, “Prayer changes things!” Thus although the members saw prayer as therapy acting at the individual level, they also saw it as an active and powerful force that could create change in the social world.

The women’s theories about intelligence, the body, healing, and prayer enabled them to deal with illness, to approach healing, and to cope with the health care system utilizing a particular framework that held meaning for them. These central beliefs that the women held and emphasized over and over in church and in their daily lives were as follows: there was a difference between intelligence and education; having intelligence meant that one recognized that only God had power over the body; it was important to count one’s blessings; illness could be caused by sin, but this might have been a sin that occurred in a prior generation and as such would not be under the control of the person experiencing the illness; there were ‘waiting times’ and one needed to learn to be patient and to trust in God’s wisdom and power; there was always hope in any situation; and prayer was the most effective way to influence healing and to create social change.
Lived experiences

In addition to understanding the women’s belief systems or theories, it is essential to recognize the reality of the women’s lives. It must be acknowledged that the women experienced all of the major medical problems that we have come to expect from people who live in poverty and/or who are subjected to continual stress and poor medical care for a variety of reasons. However, the purpose of this section is not to reiterate the women’s health problems, nor to discuss actual health encounters, but to give the reader a sense of some of the feelings that the women shared about their health care experiences. These feelings relate directly to the development of the women’s belief systems about health and health care.

There were two major ‘feeling-level’ concepts that were repeated often as the women talked about their experiences in the health care system: the feelings of fear and distrust. The pastor’s wife was extremely frightened of doctors and hospitals. She described her feelings, “You know, fear of the unknown. I get so scared. Oh, my stomach, my heart. My husband practically has to drag me.” She knew it was “silly” but she could not help it. She spoke often about her doctor’s nurse who “knew about black people” and soothed her gently with conversation about her garden. When one of the adolescents in the church needed minor surgery, the girl was extremely frightened and could not speak when the doctor asked her questions. The pastor’s wife commented about this situation, “You know how black women are — scared of the doctor — she thinks she will die because people go in the hospital and never come out.” If the pastor’s wife had to go to the hospital, she preferred the Catholic Hospital because the sisters would pray with her and the priest would come. Another church woman protested at this choice of hospitals, however, saying she had heard that they “experiment” on people in this same hospital. This woman was terrified when she had had to spend the night in a hospital and begged to go home the next day. She was afraid of the openness of the hospital, and she felt that anyone could wander in off the street and hurt her. The church members expressed similar fears in other areas. They spoke of deeply held fears in isolated areas of town, or in heavily wooded areas, or they described fear of the dark in unfamiliar parts of town. One woman explained her fear of the woods, saying, “Just the woods, the woods!” Her daughter elaborated, “There’s too much woods to disappear into.” One man’s comment about his fear of the dark was revealing: “I’m not scared of the dark; I’m scared of what’s in the dark.” They acknowledged that their fear of the woods and the dark, like their fear of doctors, might be “silly,” but they could not get around it.

hooks’ (1992) notion about how “whiteness makes itself felt as a terrorizing imposition” in black life is applicable to this discussion. People of all races who have been trained by the dominant order have been taught to see whiteness as “synonymous with goodness, with light, with safety” (p. 341). Because white people see whiteness in this way, they assume that black people (and others), conceptualize whiteness in the same way. However, hooks demonstrates that to black people whiteness “makes its presence felt in black life as a terrorizing imposition, a power that wounds, hurts, tortures …” (p. 341). Njeri (as cited in hooks, 1992) sees that her own terror with white people and white institutions is linked “with the history of the black people in the United States, seeing it [as] an imprint carried from past to present” (p. 342).

In the absence of the reality of whiteness, I learned as a child that to be ‘safe,’ it was important to recognize the power of whiteness, even to fear it, and to avoid encountering it. There was nothing terrifying about the sharing of this knowledge as a survival strategy … (p. 344).

To hooks (1992) the terror is confounded by the fact that whiteness is masked as a benign, even benevolent representation which “obscures … the sense of threat” (p. 345). She adds,

The eagerness with which contemporary society does away with racism, replacing this recognition with evocations of pluralism and diversity which further mask reality … has become a way to perpetuate the terror by providing a cover, a hiding place. Black people still feel the terror, still associate it with whiteness, but are rarely able to articulate the varied ways we are terrorized because it is easy to silence by accusations of reverse racism or by suggesting that black folks are merely evoking victimization to demand special treatment. (Ibid).

Some might ask: “Isn’t this going a bit far — seeing major institutions, systems and policies as ‘terrorizing’?” However, McIntosh (1995) points out that we are often taught to “recognize racism only in individual acts of meanness by members of [our own] group, never in invisible systems conferring unsought racial dominance on [our] group from birth” (p. 13).

Realistically, the women’s fears were based on actual experiences with life and death that took place within the context of the dominant white health care system. When Missionary Lake was ten years old she saw her father die of diabetes after having had both legs amputated. Her maternal aunt suffered the same fate and the family believed that she had become a diabetic
when the doctor started giving her insulin shots before she needed them. Both Sister Jackson and Sister Strong had come close to death as children from ruptured appendices. Both were treated in hospitals for months, far from their rural homes, as the doctors fought their infections without antibiotics. Sister Strong’s mother died at age 40 from a “real bad heart problem,” and Sister Strong herself lost five infants who were “blue babies.” The pastor’s wife’s mother had 21 children but only nine of them lived. She herself was only 16 when her mother died. Sister Smith had come close to death from an IUD infection. Sister Lander, a young church mother, had had one stillborn baby in the hospital and a second baby who died of leukemia at six weeks of age. These traumatic events in the lives of these women, most of which occurred when the women were children or young women, no doubt affected them. Thus the fear of doctors and hospitals, like hooks’ terror of whiteness, came from perhaps unrecognized associations of whiteness and doctors and hospitals and physical pain and mortal sorrow.

“I don’t trust ’em’”

hooks’ idea of whiteness as a terrorizing presence as well as the actual traumatic experiences the women had suffered, seemed to relate to this issue of fear that some of the women described. However, an even more common reaction to health care interactions, was a sense of uneasiness, of mistrust, perhaps of cognitive dissonance, of the women’s belief systems or their definition of self or their understanding about what was going on between clinician and patient.

The women themselves talked openly about this sense of distrust. Sister Lander, a 40-year-old mother of four, told me, “I don’t trust ‘em” (doctors). When her six-year-old daughter, Shani, was hospitalized for kidney surgery (she had been born with a defective ureter and risked losing a kidney), Sister Lander was clear that she would not leave the child in the hospital without a family member, and she would only leave those family members whom she could trust to speak up assertively. Her distrust was obviously warranted when Shani became more and more ill after surgery, stoically refusing to speak or sleep or move or admit to discomfort. While Sister Lander and Shani’s grandmother watched their child uneasily for two days, the doctors tried to discover the source of the problem, finally recognizing that Shani’s ureter had not been reconnected to her bladder during surgery. Although the mother had spoken to the experienced faculty surgeon at the children’s teaching hospital, and been assured that he would be doing the surgery, one can not help but wonder if the surgeon would have made such a gross error, or if, in fact, someone else, possibly a student, did the surgery.

Sister Lander told another story about a time when her youngest daughter Bebe had meningitis. The lab results confirming the diagnosis had not yet come back when the clinic sent Bebe home on antibiotics. The mother, without knowing the lab results, was told to bring Bebe back to the clinic the next day, but Bebe was sleeping soundly and Sister Lander decided to wait. Soon the police came to the door and told her to take Bebe to the hospital. Although the police were “real nice” and Sister Lander “understood,” she was surprised at the presence of the police and wondered why the clinic had not tried to call her first.

There were other situations where the women expressed their distrust and uneasiness regarding doctors and control issues. Missionary Lake told me, “You can’t contradict no doctors.” Sister Lander replied, “It doesn’t do much good.” Missionary Lake fumed angrily after her meetings with the medical evaluation team on the placement for her disturbed grandson, saying “Who know that child? You do! You raised him! … I know his problem, know how to handle him.” She complained bitterly about the “medical terms” doctors used when “you know that child!”

Marie Jones, a 50-year-old church member, described a time when she was hospitalized and near death from an IUD infection. She told the nurses that her ex-husband, a physician, would be calling to consult, but the nurses thought she was hallucinating, not believing that Sister Jones, a black woman, could be married to a doctor. Her care changed dramatically when her ex-husband, a physician, advocated for her. Sister Lander told another story about how she had watched the doctors in the labor and delivery room have a race to see who could stitch up a patient the most quickly after the woman had given birth. Sister Newton, a woman who had a child in her thirties, told the doctors she did not want spinal anesthesia during labor and “not to mess with my back,” but states that the providers tried to “psychologize” her into having the medication. Although she had requested a tubal ligation after birth, the doctors refused to do the procedure after her baby was born, and, without giving her any explanation, simply said that she would have to return several months later for the procedure. The doctors put her on birth control pills even though she was hypertensive and anemic.

These stories were not dissimilar to the stories of many women of all races and ethnic groups (Singer and Baer 1995; Martin, 1987). However, the possibility that the women’s treatment was due to racism on the part of the health care providers, was an additional factor for them to contend with and try to process during vulnerable times.
Did Taussig’s (1980) “reification” or Scheper-Hughes and Lock’s (1987) ‘objectification process’ enter into these experiences? Many of the women’s experiences suggested that these ideas were applicable. The women’s reports supported the idea that a social relationship of control that sustained the dominant order was at play. Although there were some positive comments about the health care providers, more often there were stories of fear, mistrust and racism. Encounters with health providers were generally, at best, an exercise in frustration fraught with wasted time, and, at worst, occasions for humiliation and a basic sense of dislocation about the validity of one’s own impressions. The women’s descriptions and experiences held a common thread: that they were being judged. Thus, Sister Lander was potentially neglecting her child’s meningitis, Sister Jones was ‘hallucinating’ about her doctor husband, Sister Newton was incapable of knowing what was best for herself. And yet not one of these women refused to go to the doctor, all of them wanted good care and they appreciated it once they had experienced it. They wanted to trust in those to whom they had entrusted themselves and their children. There was just little or no evidence that this was a wise thing to do. They were accustomed to their treatment; and stated, “I just go ahead on.” But it did not feel good.

But were these women unknowingly objectified? Absolutely not!! They resisted passively when they were in the middle of the encounter (averted gaze, refusal to ask questions, refusal to accept medication, monosyllabic answers), and they resisted actively with loud storytelling and complaining when they were among friends and relatives. The younger adolescent women were sometimes ‘unknowing’ about the control issues involved, but as they grew in experience, this social relationship of control became more and more apparent to them. Whether the women were ‘knowing’ or ‘unknowing,’ however, they never gave up their position as subject and they never ceased to influence the interchange.

The women’s critique: the gaze that judges and the gaze that looks back and sees

One of the most important ways in which the women demonstrated their understanding (their ‘knowing subjectivity’) of how the health care system objectified them was in their interpretation of the meaning of health care statistics. From a research point of view, the women ‘fit’ the reported statistics for health problems for African American women. As a researcher, I assumed that the women accepted these statistics, were concerned about them, and might have some insights about why their health was statistically so problematic. However, when the women were asked: “Why do you think the infant mortality rate for African American babies is so high?” or “What do you think are the causes for the hypertension rates in African American women?” the women gave some startling answers.

These answers demonstrated that the women understood that there was far more to the statistics about them than “objective facts.” Like Brown (as cited in Singer and Baer, 1995), they rejected “the widely held belief that epidemiology is a value-free scientific activity” (p. 364). Since the women (as was discussed earlier in the paper) distinguished between “education” and “intelligence,” they did not automatically believe that statistics were true, simply because educated people had generated them. From the women’s perspective, experience, not education, was the criterion for intelligence. Hence, distant statistics were not necessarily to be believed, unless they fit with one’s lived experience or with the experience of a trusted friend or relative. Although the women knew that they had health problems, their comments demonstrated that they understood that the purposes of health care statistics were often not to their benefit. In fact, they saw clearly that the health care discourse about them judged them, researched them, presented them to the public and ultimately hurt, rather than helped them. This extremely profound and revealing aspect of the women’s critique can be seen as “the gaze that judges and the gaze that looks back and sees” (Abrums, 1995).

A specific example will help to clarify the women’s viewpoint. When asked about infant morbidity and mortality rates, the women said that they did not know of babies who had died or who had been ill. At times they gave this response even when there were family members with children who were developmentally disabled or when infants in the family or church had died. But when confronted with this discrepancy, the women said they did not see these babies as part of the statistics. They stated that there was far more to the statistics about them than “objective facts.” Like Brown (as cited in Singer and Baer, 1995), they rejected “the widely held belief that epidemiology is a value-free scientific activity” (p. 364). Since the women (as was discussed earlier in the paper) distinguished between “education” and “intelligence,” they did not automatically believe that statistics were true, simply because educated people had generated them. From the women’s perspective, experience, not education, was the criterion for intelligence. Hence, distant statistics were not necessarily to be believed, unless they fit with one’s lived experience or with the experience of a trusted friend or relative. Although the women knew that they had health problems, their comments demonstrated that they understood that the purposes of health care statistics were often not to their benefit. In fact, they saw clearly that the health care discourse about them judged them, researched them, presented them to the public and ultimately hurt, rather than helped them. This extremely profound and revealing aspect of the women’s critique can be seen as “the gaze that judges and the gaze that looks back and sees” (Abrums, 1995).

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statistics were framed and presented, they were utilized to make a group of people, a race, look bad, weak, diseased, uneducated, and unable to care for themselves and their children. The women saw that health research had rarely been to their benefit — rather that others benefited economically while they remained the ‘guinea pigs’ and looked worse and worse on paper.

The women noted that the research system, like other institutions, perpetuated itself by pumping out more data, and that studies were developed so somebody else (never them) could make money. Thus any health statistics were highly suspect because they were heavily influenced by both “the almighty green dollar” and by racism. The statistics were also suspect because they belied the women’s experience of having taken good care of themselves and their children. Embroiled in this whole issue of women of color, subjectivity and medicine, and at the heart of the women’s critique, is the issue of public policy. Health professionals commonly believe that public health policy is based on scientific, biomedical research. However, the women’s critique demonstrates that one of the unrecognized dimensions of social and scientific systems such as health care systems, is that myths and stereotypes are often disguised within scientific as well as within historical research. This idea does not assume intent, i.e. that racism is purposefully perpetuated by the way statistics are presented, rather it demonstrates function, how the statistics function in the society. The manner in which statistics have characteristically been translated into supposedly benevolent public policy supports the same function. Thus the statistics function, not just to make a group look bad, but also to provide support for continuation of projects that perpetuate the dominant order — the continuation and growth of the health care and research industries.

There are several ways in which statistics, purposefully or inadvertently (it really does not matter) serve these functions. hooks’ (1992) idea of the concept of ‘white’ as good and ‘black’ as bad comes into play here, as does Harding’s (1986) notion about the damaging aspects of projects which compare one group to another, thus creating a ‘universal other’ without power or history, an ‘other’ that is more dissimilar than similar. As Cooper and David (1986) point out:

... races do exist. They are a powerful force in determining health, not for biological reasons, but for social reasons. Black people in our society are imprisoned by institutional racism: This is the attribute of blackness which at bottom determines their health status (p. 114).

The stereotypes which underlie the presentation of health statistics regarding people of color function as political myths which justify racist policy and approaches. While perhaps not as seemingly deadly as Stannard’s (1989a,b) analysis of the function of political myths in the colonization of the Hawaiian natives or Taussig’s (1987) description of the use of these myths in exterminating and controlling the natives of the Puntamayo, these stereotypes are just as damaging in their own way. There is really not much difference between the colonizer’s myth of the ‘pre-contact’ Hawaiian people as diseased, weakened barbarians committing infanticide, and today’s statistics which represent African Americans as having more physical problems than other races, or statistics which imply that black infant mortality rates are related to prenatal neglect. As hooks (1992) states:

Stereotypes, however inaccurate, are one form of representation. Like fictions, they are created as substitutions, standing in for what is real. They are not to tell it like it is but to invite and encourage pretense. They are a fantasy, a projection onto the Other that makes them less threatening. Stereotypes abound when there is distance. They are an invention, a pretense that one knows when the steps that would make real knowing possible cannot be taken — are not allowed (p. 343).

The most important issue to be raised by the church women’s critique, is not that the statistics have been and are often racist, (although this too is very important), but rather that statistics presented in a racist framework prevent policy makers and caregivers from questioning the true causes for the poor health of some African Americans and of other groups in poverty or on the margins. Thus the manner in which the statistics are framed provides a screen, a distracter, from what is really going on. Statistics that blame the victim obscure the fact that it is the statistics that support the myths that sustain the conditions. The women’s critique, is not that the statistics have been and are often racist, (although this too is very important), but rather that statistics presented in a racist framework prevent policy makers and caregivers from questioning the true causes for the poor health of some African Americans and of other groups in poverty or on the margins. Thus the manner in which the statistics are framed provides a screen, a distracter, from what is really going on. Statistics that blame the victim obscure the fact that it is the statistics that support the myths that sustain the conditions.

Meaning and subjectivity: “You don’t know because I’m not yours”

The women of Morning Sun might not have had control over all of the effects of poverty, racism and sexism in their lives, but they could and did refuse some of the information from the dominant ideology that attempted to objectify, control and judge them. They could and did ‘remain subject’ in the face of the objectifying data and the control of the health care system because of a core meaning system that sus-
the women had developed a healthy skepticism about their encounters with the health care system and the information generated by the system about them. They had created a meaning system that enabled them to understand their experiences and to take control of their own healing. The anchor for this meaning system that overshadowed all other influences was the belief that the body was a gift from God and that only God had the ultimate say over what would happen to the body. An “intelligent” person recognized and believed this. This belief did not emerge solely as a reaction to oppressive forces, rather it grew primarily from a creative center within the women. This belief, along with the ability to critique the health care system from the margins (which was facilitated by their knowledge that education did not always beget intelligent information), enabled the women to cope when they encountered the health care system.

A final story will best illustrate how the women enacted their subjectivity. A visiting preacher, Sister Light, told of a time when she was in a coma with a body temperature of 60 degrees when the doctors said, “No way!” and gave her 12 hours to live. She said adamantly:

I admire doctors but they don’t know it all. Doctors don’t accept nothing they don’t understand!! Doctor said he was ready to sign my death certificate, but I said “Doctor, you don’t know, because I’m not yours!!”

When the women told this and other stories about God’s power over the doctor (told over and over again), their beliefs about God’s power were solidified and the frailty of the human doctor was reinforced. When the women told stories such as this one, they were strong and justified, happy and powerful. They held a truth that few people knew.

The women of Morning Sun remained in control in their encounters with health care because of their belief system. They knew and chose Who was really in control. If anyone became an object, it was the doctor as Jesus used his hands, brain and heart for healing the sick. This belief system was not simply a reaction to the power and control of the dominant society. Rather, it was centered in the knowledge that the body, like the perfectly symmetrical stripes on the watermelon, was a beautiful gift from God. The power to ‘change and rearrange’ and heal the body remained firmly in the hands of God. Thus, the women remained subject by choosing their own Healer.

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References


