ENGAGING THE POWER OF PRAYER: PROMOTING AIDS AWARENESS WITHIN THE BLACK CHURCH

by

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A dissertation submitted to the Graduate Faculty in Sociology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

2007

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This manuscript has been read and accepted for the Graduate Faculty in Sociology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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Abstract

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This dissertation examines how AIDS was framed as a social problem for the Black Church. The Balm in Gilead is a religious community-based organization that encourages the Black Church to address HIV/AIDS. It has been argued that the Black Church is the most influential institution within the Black community and until the Black Church comes to terms with the various issues surrounding HIV, many in the Black community will continue to ignore the threat of HIV. Due in part to the stigma associated with HIV/AIDS, many Black churches have been hesitant to respond to the illness within their congregations and communities. This project examines The Balm in Gilead's role in initiating the Black Church AIDS movement. This research also examines the reconstruction of church appropriate AIDS facts and the marketing of these facts to Black churches. The theoretical framework for this project relies heavily upon the sociology of knowledge and the social constructions of health, illness, and AIDS. Methodologies include ethnography, in-depth interviews, and content analysis.

Acknowledgements:

I would like to first and foremost thank Prof. Barbara Katz Rothman for her hard work and encouragement. There are not enough words to express my gratitude. I also thank my dissertation committee Prof. Leith Mullings, Prof. Lisa Jean Moore, and Prof. Juan Battle for their invaluable comments, contributions, and suggestions. Their enthusiasm about this project has been an excellent motivator for me. I also thank Prof. Gail Smith and all those who selected my dissertation to receive the MAGANET Fellowship. This great award has provided me with the funding needed to complete this dissertation.

I am quite fortunate to have such wonderful colleagues at the Graduate Center and would like to thank all those who have helped me formulate my ideas. I particularly thank Alia Tyner-Mullings, Nikisha Williams, and Colin Jerolmack for reading everything from early outlines to multiple drafts of the dissertation. Your insightful comments made this a much better final product.

I also thank Louise Gumbs for her patience, help, and support. I thank the rest of my family and friends, particularly my mother and my close friend, Robert, for their support and well wishes.

I would like to thank Dr. Estelle Dish, Dr. Nancy Lopez, and Mrs. Millicent Riggins, my professors and advisors at UMass, Boston, for recognizing my potential and encouraging me to apply for doctoral studies in the first place.

Importantly, I would like to thank Pernessa Seele and all those who allowed me access to the world of Black Church AIDS activism. Without your help, there would be no dissertation.

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Chapter 1:

Introduction

Introduction:

Twenty-five years ago, a Los Angeles doctor first reported to the Centers for Disease Control and Prevention (CDC) a strange "sickness" among five gay men. Since then, what has come to be known as the autoimmune deficiency syndrome, or AIDS[1], has completely changed the world in which we live. AIDS has challenged notions of sickness and health because often those infected with AIDS can be physically healthy but technically sick. AIDS has also given rise to a number of conspiracy theories regarding its origins and efforts to treat and prevent it and have cost economies around the world many billions of dollars. Faced with the possibility of death from AIDS, members of marginalized groups and communities in the U.S. ranging from the gay men of the AIDS Coalition to Unleash Power (ACT-UP) (Cohen 1998; Stoller 1998; Gamson 1991) to the sex workers of the California Prostitutes Education Project (later renamed California Prevention Education Project) (Stoller 1998) mobilized to bring awareness of AIDS, its medical treatment and services.

As a social and medical phenomenon AIDS has shed light on the effect that societal views and cultural beliefs have on how we understand illness and disease. In this dissertation I explore how AIDS is socially constructed and the process by which AIDS

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[1] A patient is considered to have AIDS, or the autoimmune deficiency syndrome, when her T-cell count falls below 200, leaving the body unable to fight off infections and illnesses. As a result, people do not actually die from AIDS but from opportunistic illnesses. The human immunodeficiency virus (HIV) is the virus commonly believed to cause AIDS.

knowledge, i.e., the information concerning its transmission and progression, is produced and disseminated. Social constructionism argues that knowledge is a product of a particular culture or society (Lupton 2000). The social construction of health and illness is central to medical sociology and helps one gain a better understanding of how social forces shape ideas of health, diagnosis, disease, illness, and death (Lupton 2000; Brown 1995). Analyzing the ways in which AIDS has been constructed does not aim to diminish the devastation that AIDS has had on the lives on millions of people around the world. As Paula A. Treichler notes, "[o]f course, AIDS is a real disease syndrome, damaging and killing real human beings… Yet, with its genuine potential for global devastation, the AIDS epidemic is simultaneously an epidemic of a transmissible lethal disease and an epidemic of meaning or signification" (1999: 11).

Although AIDS is an illness with very real symptoms and often results in very real death, AIDS, like other diseases, also has a number of associated meanings (Freund and McGuire 1999; Lorber 1997; Weitz 1991; Goldstein 1990). It is a syndrome of a weakened immune system, caused by a virus that is spread through bodily fluids, but AIDS is more than simply an illness. What we know about AIDS is derived from the meanings we associated with the taboo nature of HIV transmission, associations linked to homosexuals, sex workers, and drug addicts. As a result, AIDS, as a disease, as well as our knowledge and the meanings we associate with it, are socially constructed (Null and Feast 2002; Freund and McGuire 1999; Barbour and Huby 1998; Epstein 1996; Weitz 1991; Goldstein 1990); or as Cindy Patton (1990) contends, AIDS is "invented." By claiming that AIDS is "invented," Patton argues not that someone created the actual disease, but that social understandings of AIDS are invented.

AIDS information and meanings – such as those associated with susceptibility, protection measures, treatment, and stigmas – have been, and continue to be, received by various communities and groups differently. I extend this notion to argue that AIDS, like all concepts that carry social significance – gender, race, ethnicity, sexuality, class, and health – are constructed differently depending on the community producing and receiving the knowledge. Consequently, knowledge and perceptions of AIDS may vary. For example, the social construction of AIDS is different for the gay community than for the Black[2] community. Since the beginning of the epidemic, Blacks have had the highest rates of HIV/AIDS (Cohen 1999). Yet it was gay men who immediately mobilized and formed the world's first AIDS service organization, Gay Men's Health Crisis. Despite the evidence of disproportionate rates of infection, most Blacks initially saw AIDS as something that did not affect them – it was commonly perceived as White gay disease (Levenson 2004; Cohen 1999; Cohen 1996). Therefore, it took members of the Black community several years to develop large-scale mobilizations[3], mobilizations that never matched those of the gay and lesbian community (Quimby and Friedman 2003; Cohen 1999).

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[2] I identify African Americans as an ethnic group comprised of people who consider themselves primarily direct descendants of Africans brought to the U.S. as slaves, and Black as a racial category that encompasses African Americans, West Indians/Caribbeans, Africans, or people from other parts of the Diaspora. I will use both when appropriate.

[3] It is important to stress that some Blacks – gay, lesbian, and straight –mobilized early on with White gays and lesbians to combat AIDS. Quimby and Friedman (2003) discuss the early mobilization efforts of Black organizations such as The Southern Christian Leadership Conference and the NAACP which in the mid-80s developed programs to respond to AIDS. Quimby and Friedman (2003, 149), however, maintain that the lack of an even earlier or greater response was due to the CDC's reticence until 1986 to highlight "race-related HIV issues".

Blacks, like all racial and ethnic groups, are diverse, and the Black community is made up of a number of smaller communities, all of which construct AIDS differently. This dissertation examines AIDS and the impact it has had on the community of Black churches, their congregants, and leaders, what I will simply refer to as the Black Church[4]. I explore how one community-based organization, The Balm in Gilead, framed AIDS as a social problem for the Black Church and created a social movement based on a reconstructed version of AIDS knowledge, encouraging Black religious institutions to address AIDS in ways that coincide with their constructions of AIDS.

Situating this Project:

Currently, Blacks have the highest HIV/AIDS rates, accounting for over half of all HIV/AIDS diagnoses in the U.S. This statistic is disproportionately high considering that Blacks were 12.3% of the total U.S. population in 2000 (U.S. Census 2006). As this dissertation discusses in detail in Chapter Five, one of the reasons cited for the high rates

[4] Originally, in studies, which discussed the Black Church, most notably E. Franklin Frazier's *The Negro Church*, the term "Negro Church" was applied; however, during the 1960s that term changed to the "Black Church" (Lincoln and Mamiya 2003/1990).

The difficulty in researching the Black Church is that it is often treated as one large monolithic organization. It encompasses many branches within Protestant Christianity, and I acknowledge that it is made up of millions of members, with thousands of ministers or pastors throughout the U.S. – from the most rural areas of the South to the urban metropolis. Though many of the beliefs and practices vary from church to church, some of the core values of the Black Church are the same. The Black Church holds a very prominent position in the Black community, with an enormous amount of political and social control. Therefore, I will examine the Black Church as an institution, but acknowledge the diversity within this institution and within individual congregations.

of HIV in the Black community was its slow[5] response to addressing the virus (Cohen 1999). The taboo topics of sexuality and drug use associated with AIDS played a role in this (Levenson 2004; Cohen 1999; Dalton 1989). These sensitive issues were difficult for many Blacks – particularly religious leaders – to discuss openly. Scholars (Brown 2003; Fullilove and Fullilove 1999; Weatherford and Weatherford 1999; Shelp and Sunderland 1992) have argued that religious influence may have played a role in this denial. The old saying, "as goes the Church, so goes the community," speaks volumes to the influence of the Church on the Black community, and since the Black Church did not address AIDS, neither did other members of the Black community.

The Black Church:

The Black Church has historically been the most influential institution in the Black Community (Carruthers, Haynes, and Wright 2005; Wilmore 2004; Brown 2003; Williams and Dixie 2003; Raboteau 2001; Billingsley 1999; Sernett 1999; Gaines 1996; Howard 1965/1989; Frazier 1964/1969; DuBois 1903/1994). Traditionally, it has been made up of seven Black American Protestant denominations that had their origins in slavery and emancipation: the African Methodist Episcopal (A.M.E.) Church; the African Methodist Episcopal Zion (A.M.E.Z.) Church; the Christian Methodist Episcopal (C.M.E.) Church; the National Baptist Convention, U.S.A., Incorporated (NBC); the National Baptist Convention of America, Unincorporated (NBCA); the Progressive National Baptist Convention (PNBC); and the Church of God in Christ (COGIC)

[5] Many Blacks mobilized against the AIDS epidemic in the early stages of its history. Yet, the early Black response to the AIDS epidemic lacked the large scale mobilizations that the NAACP and the national Urban League organized during the Civil Rights Movement. Other groups – excepting, of course, the gay and lesbian community – had similarly slow responses to the crisis.

(Lincoln and Mamiya 2003/1990). New Christian denominations with Black leadership continue to develop, and often these new houses of worship model themselves on the traditions of the Black Church. This dissertation is less concerned with defining what the Black Church is than what the Black Church does and what it means to millions in the Black community. In discussing the importance of religion in the lives of African Americans, Mary Pattillo-McCoy (1998) writes:

> According to domestic and transnational polls on religious beliefs and commitment, 'American Blacks are, by some measures, the most religious people in the world'. This intense religiosity refers to the great importance of God and religion in African Americans' lives, the high frequency of church attendance and church membership, and the prevalence of prayer in daily life. Even among Blacks who claim no religious affiliation and have not attended church since age 18, 40 percent report praying everyday. (767)

According to Wimberely (1979), for many Blacks, "during slavery, Reconstruction[6], and the Great Migration[7], the Black Church served magnificently as an extended family for persons who had been separated from their families" (95-96). This tradition of family and community continues today. Since Blacks were denied access to public space and civic institutions for much of American history, "the Church act[ed] simultaneously as a school, a bank, a benevolent society, a political organization, a party hall, and a spiritual base [it was] often the center of activity in Black communities" (Pattillo-McCoy 1998: 769). Because of this, the Black Church has played a key role in

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[6] Reconstruction lasted for almost 10 years after the end of the Civil War and refers to the historical period and process by which Congress restructured the South.

[7] The Great Migration was the movement of millions of African Americans from the South to large cities in the North, such as New York, Chicago, Detroit, and Philadelphia. This movement occurred from the early to mid-1900s.

political and social justice activities, (Lincoln and Mamiya 2003/1990)[8] and is also known for, "promoting racial awareness… social service provision, and psychosocial well-being" (Ellison and Sherkat 1995: 1416). However, research on the Black Church shows that the centrality of the Black Church in the lives of African Americans varies by age, gender, marital status, and even geography.

In their 1995 ethnography, Ellison and Sherkat argue that the Black Church was a "semi-involuntary institution" for Blacks in the rural South. They argue that in the South Blacks are expected to join a church. Due to the direct link with slavery, racial segregation and discrimination during the Jim Crow era, and the prohibition of Blacks from gathering for reasons other than religion, the Black Church took on a central role in the lives of Blacks in the South. Conversely, according to Ellison and Sherkat, in cities, particularly in the North, "the availability of (1) a wider range of secular lifestyles and (2) secular sources of benefits usually provided by the [C]hurch in rural southern communities may make urban religious institutions less central, and participation in them more voluntary" (Ellison and Sherkat 1995: 1416).

[8] There is a debate as to how progressive the Black Church actually is. Though the Black Church is credited with organizing the Civil Rights Movement, many Black religious leaders and congregants wanted to take a less aggressive approach to fighting for equality. Such debates encouraged Martin Luther King Jr. and other religious leaders to separate from NBC and form the Progressive National Baptist Convention in 1961. However, there were still many Black churches that actively participated in the civil rights movement and fought for Black equality. In fact, "for decades prior to the rise of the Black secular press, the Black Church papers served as a major protest instruments against racism through the dissemination of information, the interpretation of events affecting the race's welfare, and advocacy for specific forms of resistance" (Paris 1985: 103).

Regardless of location, middle-aged/older, married women are more likely to attend church. Despite these differences, an early 1990s National Survey of Black Americans found:

- 84% of African American adults considered themselves to be religious;
- 80% considered it very important to send their children to church;
- 78% indicated that they pray often;
- 76% said that the [C]hurch was a very important institution in their early childhood socialization;
- 77% reported that the church was still very important;
- 71% attended church at least once a month; and
- nearly 70% were members of a church (Billingsley and Caldwell 1991: 428).

Thus, it is relatively safe to say that religion and spirituality play a major role in the lives of most Blacks, and that religious institutions have the capacity to reach the largest number of Blacks. This confirms Wilson's (2000) finding that Black religious institutions would be the ideal place for health promotion activities and AIDS awareness programs. Yet, there was great hesitation on the part of many Black Church leaders and congregants to provide help or even mention HIV, lest they be perceived as condoning the behaviors associated with HIV transmission (Brown 2003: Weatherford and Weatherford 1999; Shelp and Sunderland 1992). This insight is consistent with my findings, which will be more fully addressed in Chapter Five. Respondents noted that many members of their congregations lost loved ones to AIDS before church leadership even mentioned the disease from the pulpit. This hesitation on the part of the Black Church illustrates the social aspects of disease. Regardless of its social role, the Black Church is still a religious institution; and like most other religious institutions, the it had

great difficulty approaching the AIDS epidemic in its early stages[9] and in seeing AIDS as a social problem for itself and the larger Black community (Cohen 1999; Weatherford and Weatherford 1999; Shelp and Sunderland 1992; Dalton 1989).

The response of the Black Church to the AIDS epidemic was similar to the response of a majority of social institutions in the U.S. during the epidemic's early years (Shilts 1987). Still, because of its history as a "freedom fighter" within the Black community – especially for race-based social justice issues – there was an expectation that the Black Church would advocate for those suffering from AIDS (Wilmore 2004; Cone 1996; Gains 1996; Williams 1987). Scholars (Douglas 2003; Quimby and Friedman 2003; Cohen 1999; Weatherford and Weatherford 1999; Dalton 1989) note that because the Black Church did not immediately respond to the AIDS epidemic, the Black community did not see AIDS as an issue that required a response. Many Blacks believed, as did the larger society, that they were not susceptible to HIV infection because AIDS was first identified as a gay-related immune deficiency syndrome (GRIDS), a "[White] gay disease" that later became something that only drug addicts, or the promiscuous could contract[10]. Moreover, since HIV is spread through what is considered by many religious leaders to be immoral behaviors, people with HIV/AIDS are often thought of as

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[9] There were a number of churches, mosques, synagogues, and other Black religious institutions that addressed HIV/AIDS at the beginning of the epidemic. These religious institutions organized everything from ministries, clothing drives, food pantries, and even housing for those suffering from HIV/AIDS. A vast majority of religious institutions, however, either ignored or actively condemned those who were HIV+ or living with AIDS.

[10] As will be described in Chapter Five, an early distinction was made between those who were "innocent" and contracted the disease through blood transfusions or babies born to infected mothers. For the most part, however, AIDS was still considered to be caused by immoral behavior.

"deserving what they get," or "receiving their punishment from God" (Fullilove and Fullilove, 1999; Weatherford and Weatherford 1999; Shelp and Sunderland 1992). Thus in the early years of the epidemic, it raged relatively unchecked throughout the Black community.

Health and the Black Church and Community:

Health concerns were nothing new to the Black community. Whether the result of poverty, lack of access to a healthy environment, or institutionalized racism, those who face the most discrimination tend to have higher numbers of health issues (Jones and Rene 1994). Blacks have the highest rates of mortality and morbidity in the U.S. (CDC 2002). Blacks rank the highest in cancer, diabetes, heart disease, and hypertension[11] in all of which are leading causes of death in the United States. These conditions become exacerbated by poverty and poor living conditions. With so many health concerns, many community-based organizations (CBOs) within the Black community have initiated health interventions. Many of these CBOs understand the plight of the people within their communities, recognizing that people do not have complete control over many of

[11] According to The Surveillance, Epidemiology, and End Results Program (SEER), the incidence and death rates from cancer are highest among Black men. Black men have an incidence and death rate from cancer at 674.5 and Black women have a rate of 405.3 (per 100,000) (2004a), and Blacks are much more likely to die from cancer than any other racial or ethnic group (2004c). They also have higher rates of diabetes than any other group, with 13% of all Blacks in the United States having diabetes (CDC 2005b). According to the American Heart Association, 40% of Black men and 41% of Black women have heart disease, and over 40% of Blacks have hypertension, which can lead to stroke, heart and kidney failure (CDC 2006a; 2006b; 2005b). The Office of Minority Health of the CDC (2006) reported that in 2000 Black women had the highest rate of infant mortality, with the neonatal and post-neonatal death rate among Blacks equal to 14.1 of every 1,000 live births compared to 5.7 among Whites. The rates of maternal mortality among Black women are 4.2 times that of White women. In fact, Whites exceed the life expectancy of Blacks by approximately 5.4 years.

the social factors – such as living conditions, diet, etc. – that influence their lives (Airhihenbuwa and Lowe 1994).

Airhihenbuwa and Lowe (1994) believe that, "given the right information and perhaps the right circumstances, individuals would be willing and able to change their health conditions" (391). The World Health Organization (WHO) has defined health promotion as "a process of enabling people to increase control over and to improve their health" (Minkler 1997: 4). During the past 20 years, communities have taken a greater role in promoting the health of individuals by not only promoting health itself, but by fighting against issues that may impede positive health outcomes such as institutionalized AIDS discrimination and institutionalized racism (Minkler 1997). Yet, the government does not have the ultimate control over one's health, individuals do (Jones and Rene 1994). As a result, many CBOs formed to address health issues – such as AIDS – in the Black community (Chambre 2001, 1995, 1999; Cohen 1999). Some of them target religious institutions in order to promote risk reduction and healthy living within the Black community.

With the help of CBOs, Black churches have tried hard to improve the living conditions of their parishioners and the members of their communities. As noted above, the Church plays a major role in the lives of a number of African Americans. As such, the Black Church serves as an extended family, and involvement within the Church can provide positive mental health outcomes as well as a key location for health interventions (Williams and Fenton 1994). Black Church leaders and congregants do everything from visiting sick parishioners in the hospital to sponsoring church health fairs (Wilson 2000). CBOs such as The Black Leadership Commission on AIDS and The Balm in Gilead have

recognized the influence that the Black Church has had and the role it can play in curbing the high rates of AIDS (Douglas 2003; Newman 2002; Weatherford and Weatherford 1999; Shelp and Sunderland 1992).

The Balm in Gilead:

As I will describe in more detail in Chapters Two and Three, The Balm in Gilead (The Balm) is a 501 c3 non-profit[12] religious community based organization. It was the first, and is currently, the only AIDS awareness organization that works exclusively with the Black Church. The Balm organizes "The Black Church Week of Prayer for the Healing of AIDS" (BCWOP), the largest HIV/AIDS campaign targeted at the Black community. It is at the forefront of a social movement challenging Black Churches to address the AIDS epidemic within their congregations and communities.

My research examines how The Balm in Gilead works within the Black Church's social construction of AIDS, how it reproduces and reframes AIDS information and knowledge to be appropriate and acceptable to this religious institution, thereby constructing a "version" of AIDS that churches feel justified in addressing. By focusing on different social constructions of AIDS and examining the Black Church's response to the AIDS epidemic[13], I will emphasize the importance of cultural and community

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[12] 501 c3 organizations are religious or educational organizations that enhance public safety. It is tax exempt and all donations to are tax deductible.

[13] HIV spread rapidly throughout the United States. Due in part to powerful safe-sex campaigns, transmission rates slowed in the late 1980s and early 1990s, but cases of AIDS continued to rise because people suffered opportunistic infections soon after being diagnosed. After the introduction in 1995 of the "the cocktail," a combination of medications used to retard the development of AIDS in HIV patients new cases of AIDS have been on the decline, but cases of HIV have been on the rise. Therefore, for the purpose of clarity and simplification, I will refer to both HIV and AIDS when I refer to the AIDS epidemic.

understandings of AIDS. I intend to show examples of the changes that can occur once an understanding of different social constructions of a disease is gained. Therefore, I examine the Black Church as both a social and a religious institution that is key to forming the Black religious experience – an institution put in a precarious predicament by the AIDS epidemic. On the one hand, the Black Church is a social institution whose historical duty has been to advance and protect the lives and freedoms of Blacks, obligating it to address an issue of this magnitude. On the other hand, the Black Church is a religious institution with particular morals, values, and beliefs – beliefs that run counter to certain AIDS awareness and prevention methods.

Much as religious experiences have shaped modern culture and influenced societal understandings (Durkheim 1912/2001; Durkheim 1951/1979; Foucault 1978/1990; Weber 1905/2002), the Black Church, since its founding almost 200 years ago, has shaped the culture, values, and experiences of African Americans (Pinn and Pinn 2002; Raboteau 2001; Lincoln and Mamiya 1990/2003). Despite the negative social and religious views that its members and leaders have of behaviors associated with HIV transmission, AIDS has forced the Black Church to address openly social issues that it has historically avoided – sex, sexuality, gender identity, and drug abuse (Brown 2003).

I decided to focus on New York City for three reasons: New York has the unfortunate distinction of having the highest HIV/AIDS infection rates in the US. As stated earlier, Blacks make up 42.2% of AIDS cases nationally, and they make up 50% of all *new* AIDS cases nationally. In 2000, Blacks made up 44.5% of AIDS cases in Manhattan, while Whites made up 23.8% and Latinos 30.5%. Also, a majority of Blacks who live in Manhattan live in Harlem.

The second reason why I selected New York City is because New York has the highest concentration of Black Churches in the United States. For example, within the estimated 47 blocks that make up New York City's Harlem, there are over 250 churches and other religious institutions, "ranging from unincorporated storefronts to historic institutions housed in magnificent church-owned edifices" (Hickman 2001: xi). In fact, on my block of 128th Street between Lenox and Fifth Avenues, there are four churches. Thus, Harlem, perhaps the most well known neighborhood in the world is also, "perhaps, the most 'churched' community' in the world" (Hickman 2001: xi).

My third reason for selecting New York City is because The Balm in Gilead is based in New York[14]. The Balm in Gilead was founded in Harlem and later moved its operations to Midtown, Manhattan.

Dissertation Goals:

This dissertation has four major goals. The first goal is to understand the social construction of societal problems. The second goal is to understand how AIDS knowledge is constructed and reproduced. I examine how knowledge production works to change HIV from something to be feared to something that can be prevented and treated and, thus, controlled. The third goal is to emphasize that the Black community and the Black Church are working to control the spread of HIV in its community, with more churches creating AIDS ministries[15] and programs. This dissertation examines how the largest HIV/AIDS prevention campaign aimed at the Black community targets the

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[14] During the time in which this research was conducted, The Balm in Gilead was based in New York City; its headquarters, however, have since moved to Richmond, Virginia.

[15] Though the nature of ministries varies at different churches, in general, a ministry is a group under the control of the church with an expressed goal, usually to help those in their community.

Black Church and encourages it to come to terms with the issues surrounding HIV in order to promote education, compassion, services, and awareness to its congregation and the larger community. More theoretically, at the root of this project is the sociology of knowledge – how societal knowledge is constructed (Gergen 2003; Hacking 1999; Berger and Luckmann 1966/1989; Mannheim 1936/1985) and perceived – and understandings of the social constructions of health and disease (Lupton 2000; Conrad 1997; Lorber 1997; Brown 1995; Conrad and Schneider 1992; Weitz 1991; Rosenberg 1989; Kleinman 1988; Conrad 1986; Freund 1982). I use the Black Church as the lens through which I examine the social construction of AIDS and argue for a deeper understanding of the social construction of AIDS and the effect of this construction on AIDS discourse and awareness within communities. As a result, my fourth and most important goal is to contribute to a better understanding of the ways in which culturally competent health information can be used to decrease health disparities among traditionally hard to reach groups.

Past research into the AIDS epidemic in the Black community tended to emphasize what the Black Church has not done (Dalton 1989; Fullilove and Fullilove 1999), why little been done (Cohen, 1999), and what needs to be done (Weatherford and Weatherford 1999; Shelp and Sunderland 1992); or it evaluated the work that is being done (White 2003; Swain 1999; Wise 1997; Quinn 1993). These previous studies neither focused on the general social construction of AIDS nor the Black Church's construction of AIDS. Neither did they examine how an organization works to re-construct or reframe prevalent social constructions of AIDS, or how the re-construction of AIDS may lead to

social action and a movement on the part of the Black Church in creating and promoting AIDS awareness.

This project is innovative in that it begins from the perspective that the Black Church *is* addressing HIV/AIDS. This project addresses *how* this is being done and focuses on a CBO that is working with the Black Church to enact social change within the larger Black community. This CBO accomplishes this by creating knowledge for the Black Church as a social institution and for individual Black Churches. Specifically, I examine the ways in which a CBO takes medical knowledge and turns it into religious knowledge for the Black Church, with the hopes of reaching the larger Black community. Thus, this CBO is equipping the most trusted organization within the Black community – the Black Church – not an 'outside' medical organization, to spread knowledge and information pertaining to HIV across the Black community.

This dissertation will contribute to scholarly work on health oriented CBOs (Freudenberg, Rogers, Ritas, and Nerney 2005) and the social construction of AIDS. It will also show the positive steps Black churches take to address AIDS, and provide a model for other CBOs that want to frame population specific health information. The primary aim of this research is to contribute to the study of the social construction of knowledge, the sociology of health and illness, social movements, and social marketing, as well as Black studies, gender studies and queer/sexualities studies.

This dissertation is organized into seven chapters including this introduction. Chapter Two explains how I conducted this research. Chapter Three describes the social movement that Pernessa Seele, the founder and chief executive officer of The Balm, created within the Black Church as well as the organization she created to sustain this

movement. The next chapter argues for the existence of different social constructions within different communities. Here I argue that though AIDS is an illness, like all illnesses it has different social meanings constructed around community understandings of AIDS. Chapter Five discusses how The Balm has taken facts about AIDS and "reframed" them in a way befitting the religious and moral stance of the Black Church as an institution and with individual Black Churches. Chapter Six explains how AIDS has become commodified so as to allow organizations such as The Balm to utilize marketing principles to create campaigns that in fact market its constructed version of AIDS to the Black Church. The concluding chapter provides examples of how Black churches have implemented the knowledge they have received from The Balm and incorporated this information in their ministries to educate their communities about the virus. This chapter also provides a discussion of contributions to the fields of sociology and policy recommendations. It includes a brief discussion of President Bush's Faith-Based Initiatives and funding.

Chapter 2:

Methodology

Introduction:

I began this research to explore the different reasons behind the high rates of HIV/AIDS in the Black community. I soon found my work focused on the Black Church and the role that religiosity plays in the lives of African Americans. I do not argue for AIDS education within the Black Church nor even suggest that it is a necessary place for AIDS prevention and awareness within the African American community. Rather, this dissertation was written to emphasize the positive work that the Black Church has taken in order to counter the myth that the Church continues to be non-responsive to the AIDS epidemic as well as explore the construction of social problems. Throughout this dissertation, I emphasize the importance of cultural understandings of how disease is perceived and addressed.

This research is conducted in an exploratory manner to better understand how The Balm in Gilead works with Black Churches to promote AIDS awareness. The research uses traditional qualitative sociological methods such as in-depth interviews, ethnography, and content analysis. Grounded theory (Charmaz 2002; Glaser and Strauss 1999) is used to analyze the data.

The background research for the participant observation phase of the study was conducted between May and October of 2004, when I began to examine how the Black Church responded to the AIDS epidemic and I was made aware of the work of The Balm in Gilead. In the early part of October 2004, I contacted Rev. Alberta Ware, the Director

of Church and Community Mobilization at The Balm, and met with her on October 25th. We discussed the work of The Balm and the Black Church in addressing AIDS. After this meeting, I sent an email to Pernessa Seele, the Founder and Chief Executive Officer of The Balm in Gilead, requesting a meeting. Six weeks later, I met with Seele and Dr. V. Ann-Denise Brown, the Director of Research and Evaluations. We discussed the history of The Balm as well as the possibility of using The Balm as the research site for my dissertation.

Gaining entrée was my first major challenge. As William Kornblum (1996) notes, "usually the most trying aspect of this kind of research is the effort to obtain permission to spend time with the people one wishes to get to know" (2). I found this especially difficult because I wanted to gain entry not only to The Balm in Gilead but also to the community of Black Church AIDS activism. Successful entrée is crucial. Quandt, McDonald, Bell, and Arcury argue that a successful entrée, "opens the way to an in-depth, comprehensive understanding of the research community in its entirety and complexity. This in turn intensifies the quality of involvement of the researcher and knowledge of the community, which increases the overall quality of the research results" (1999: 113). Considering the sensitive nature of my research, it was pertinent that I gain the trust and acceptance of those at The Balm as well as other religious leaders and community members. I stressed to Seele and Brown that my research was exploratory – not "intentionally evaluative" (Greene 1994). Realizing that Brown was, as Seidman (1998) calls, the "gatekeeper" for The Balm, I spent three and a half months calling and

emailing her until I was finally granted permission to use The Balm in Gilead as the site for my fieldwork[16].

Ethnography[17] and Participant Observation:

The data collection for this project consists of ethnographic research methods, which Atkinson and Hammersley (1994) argue should consist of the following:

- A strong emphasis on exploring the nature of particular social phenomena, rather than setting out to test hypotheses about them
- A tendency to work primarily with "unstructured" data, that is, data that have not been coded at the point of data collection in terms of a closed set of analytic categories
- Investigation of a small number of cases, perhaps just one case, in detail
- Analysis of data that involves explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations (248).

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[16] I believe that being a Black woman who grew up in the Black Church, with an understanding and knowledge of it, significantly helped me gain entry not only into The Balm but also to church events and interview participants. In addition, there is a long tradition of education being highly regarded within the Black community, and especially among "church folk." My honesty with my participants as well as my status as a Black, female, graduate student who grew up Baptist made my data collection relatively easy (Dunbar, Rodriguez, and Parker 2002). In fact, many of my respondents, including Pernessa Seele (the Founder and Chief Executive Officer of The Balm) were very excited that their work was being acknowledged and recorded.

[13] Though the research for this dissertation was gathered in a traditionally ethnographic manner, the "form" (Altheide and Johnson 1994) of my writing is not presented as such. For example, I do not provide rich descriptions of research sites as does Whyte's *Street Corner Society* (1955), Leibow's *Tally's Corner* (1967), or Dunier's *Sidewalk* (2000), of the offices of The Balm or of the churches where I conducted my research. In these books, such a description was necessary to get a feel of the community and location being studied -- because the setting was just as important as the cast of characters. This was not the case with The Balm. In my research, I was more concerned with what is being produced/discussed in these settings. The physical make-up of the location was not an integral part of my research. As a result, though not written in a typical ethnographic style, my ethnographic approach is still critical to gaining an understanding of and trust in my research environments.

My fieldwork took place between February 2005 and May 2006. My work at The Balm was essential for my understanding of The Balm as an organization as well as the unique issues that many Black Churches face in addressing AIDS. Gaining the trust of Balm employees was important for me to gain access to information and materials. I volunteered at The Balm in Gilead three days a week for six to eight hour shifts between February 24th and July 28th, 2005. After that time, I returned to The Balm periodically to both visit and help out on projects. While there, I got a feel for the organization and access to an enormous amount of information concerning the way The Balm operates. I also obtained Balm produced educational materials such as videos, brochures, pamphlets, booklets, and publications. My time on site helped me determine the best people to interview and the types of material best suited for my analysis.

In addition to the time I spent at The Balm, I also participated in a number of Black Church Week of Prayer events. I attended Timothy Baptist Church's Prayer Vigil in 2005, Harlem Congregations for Community Improvement's HIV/AIDS Prayer Vigil in 2006, the play "Love Thy Self" by Sundi Lofty, that was performed during Emmanuel Baptist Church's 2006 Week of Prayer event, and a number of conferences, panels, and events throughout Manhattan, Brooklyn, and the Bronx, as well as worship services at these churches. It was at these events that I approached potential participants about my research, requesting interviews and discussing the development of AIDS ministries within their churches, their experiences with the Black Church and AIDS, as well as any work they may have done with The Balm in Gilead.

In the field, I recorded notes and observations in a small notebook that I carried with me at all times. I made note of the type of work I did at The Balm, staff interaction,

and Balm and Church communications, the types of words used, materials distributed (which I collected for content analysis), and the gender and racial distribution of the participants (Junker 1960). Upon arriving home, I would type up my field notes, producing dozens of pages of notes that I later analyzed.

In-Depth Interviews:

Conducting in-depth interviews enhanced the information I obtained through my participant observations. In discuss the importance of in-depth interviews, Sue Jones (1985) contends that:

> To understand other persons' constructions of reality we would do well to ask: them (rather than assume we know merely by observing their overt behavior) and to ask them in such a way that they will tell us in their terms (rather than those imposed rigidly and *a priori* by ourselves) and in a depth which addresses the rich context that is the substance of their meanings (rather than through isolated fragments squeezed onto a few lines of paper). (46 [italics theirs])

While working at The Balm, I selected a number of people who would be of interest to my project, either because of positions they held at The Balm or their knowledge of The Balm and the Black Church's response to the AIDS epidemic. As Seidman (1998) notes, it was necessary for me to understand not only people's experiences, but how they come to understand such experiences. This led me to use purposeful sampling measures (Seidman 1998) to select four different categories of people: 1) Balm employees 2) church leaders and/or ministry leaders 3) Certified Service Partners and 4) activists. By interviewing these people with different perspectives on the AIDS epidemic in the Black community, I gained a better understating of the meanings associated with AIDS and the perceptions of AIDS within individual Black Churches.

Since my research is a case study of The Balm's work with Black churches, my research is not overtly generalizable (Yin 2003a; Yin 2003b). My sample is purposeful

and participants were selected primarily through the snowball technique (Seidman 1998). I examined those churches and individuals who had direct connections with The Balm, those who, for example, received technical assistance, were current or former employees, or knew and admired the work of The Balm. Nonetheless, due to the exploratory nature of this project, I was not focused on the generalizability of my sample, but on the relationships that my respondents – the churches, Certified Service Partners, and activists – had with both The Balm and the Black Church.

After working at The Balm in Gilead for three months, I conducted my first semi-structured, in-depth interview (McQuiston, Parrado, Olmos-Muniz, and Martinez 2005), and between May of 2005 and June of 2006, I conducted 27 more interviews (see Appendix A for sample questions). I met all but two of my respondents in person before requesting an interview. I approached 32 people to participate in this project and all but five agreed. I met most of my respondents while working at The Balm and at Black Church AIDS events and meetings. There I was able to use my connection to The Balm to secure interviews. A majority of my interviews were face to face and were conducted in respondents' homes, places of employment, or church. Five interviews were conducted over the phone.

Before conducting the interview, I explained the research project and informed respondents of their rights and had them sign a consent form[18] (Seidman 1998). These

[18] A note on the protection of human subjects:
Confidentiality was only provided and protected upon request. I informed all participants of their right to remain anonymous prior to the interview, and two people from my "church" sample selected this option. However, I made a decision prior to my data collection not to interview anyone who chose to remain anonymous who worked for The Balm because of my inability to secure their anonymity; this did not become an issue. The interviews were audio recorded after informants had agreed to participate and signed

interviews were all audio-recorded on a digital voice recorder, and ranged from 11 minutes to two hours in length. These interviews were then uploaded into computer software and transcribed on a computer. Though I gave all of my respondents the option for confidentiality, all but two of my respondents agreed to be identified by name. A majority of my respondents were female (n=17), all were Black, and all identified as Christian. There were eight ordained Christian ministers in my sample.

The Balm:

When I first began volunteering at The Balm, there were 15 employees. My selection criteria were based on the positions they held within The Balm and their knowledge of the history of the organization. I interviewed the following Balm in Gilead employees:

- **Pernessa Seele**, Founder and the Chief Executive Officer of The Balm in Gilead, interviewed in 2005 and 2006;
- **Rev. Evatt Mugarura**, Director, Africa HIV/AIDS Faith Initiatives interviewed in 2005;
- **Darlene Cheek**, Certified Service Partners Coordinator and Coordinator of Resource Center, interviewed in 2005;
- **Nguru Karugu**, International Program Manager, interviewed in 2005;
- **Teresa Lyles Holmes**, Media Relations Consultant, interviewed in 2005;
- **Rev. Alberta Ware**, Director, Church & Community Mobilization, interviewed in 2005;
- **Dr. Joyce Moon-Howard**, Balm Board Member and Professor at the Mailman School of Public Health, Columbia University, interviewed in 2005;
- **Tonya Perry**, Authored Balm Publication and Assistant Professor of Social Work at Fordham University's Graduate School, interviewed in 2005.

I asked informants how they became involved with The Balm in Gilead, the ways they address AIDS stigma within the context of the Church, the Church's role within the Black community, and what they believe they provide to these churches. I inquired about

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the consent form. The interview digital files were stored on a password-protected computer to which only I had access. The consent form and printed transcripts are stored in a locked file cabinet in a secure location.

the history of The Balm, their roles in spreading HIV/AIDS discourse to the Black Church, and the changes the Black Church made concerning HIV/AIDS. Through these interviews, I not only obtained a better understanding of how The Balm works with churches, but the unique issues that Black Churches faced in addressing AIDS within their congregations and communities. The supplementary interviews with Seele presented in this dissertation came from three sources: Erica L. McKnight's 2005 interview with Seele and Dorie Gilbert's 2003 interview. I also used other published magazines and newspaper articles with interviews of Seele as data.

Churches:

I contacted pastors, AIDS ministry leaders, and volunteers at seven Brooklyn, Manhattan (Harlem), and Bronx churches to analyze how The Balm works with churches, how they are received, and how measures to address HIV/AIDS are employed. These interviewees were selected based on the types of AIDS events they held within their churches and on their relationships with The Balm. I interviewed the following:

- **Angela Griffin**, Ministry Leader of Berean Baptist Church in Brooklyn, interviewed in 2005;
- **Latrice Wactor**, Co-Ministry Leader of Abyssinian Baptist Church in Harlem, interviewed in 2005;
- **Rev. Claudette Davis**, Ministry Leader of Timothy Baptist Church in Brooklyn, interviewed in 2006;
- **Pastor Odelle Davis**[19], Timothy Baptist Church in Brooklyn, interviewed in 2005;
- **Cheryl Sullivan**, Ministry Leader of Emmanuel Baptist Church in Brooklyn, interviewed in 2006;
- **Geneva Musgrave**, Ministry Volunteer of Emmanuel Baptist Church in Brooklyn, interviewed in 2006;
- **Sundi Lofty**, Playwright, Emmanuel Baptist Church in Brooklyn, interviewed in 2006;

[19] Rev. Claudette Davis and Pastor Odelle Davis are unrelated, but both work at the same church. In order minimize confusion when citing them, I will use the first initial of Reverend and Pastor Davis.

- **Pastor Anthony Trufant**, Emmanuel Baptist Church in Brooklyn, interviewed in 2006;
- **Fatima Prioleau**, Ministry Leader of Agape Tabernacle in Brooklyn, interviewed in 2006;
- **Anita Parker**, Ministry Leader at St. Luke AME in Harlem, interviewed in 2006;
- **Jennifer Smith** (pseudonym), Ministry Leader at an AME church in the South Bronx, interviewed in 2006;
- **Rev. Michael Jones** (pseudonym), AIDS Ministry Liaison and Assistant Pastor at a Baptist Church in Harlem, interviewed in 2006.

I interviewed them about their experiences with The Balm and the types of programs they organize within their churches. I also inquired about some of the obstacles they faced in addressing AIDS, such as the taboo topics associated with homosexuality, sex, and drug use.

Certified Service Partners:

After working at The Balm for a few months, I became aware of what The Balm called Certified Service Partners – organizations that worked directly with The Balm and churches within their local communities. These organizations not only participate in the Week of Prayer, but organize their own AIDS awareness events. People from these organizations also receive training by The Balm as to how to best address AIDS within a religious context. I interviewed the following:

- **Deborah Levine**, Vice President of Community Development of the National Black Leadership Commission on AIDS, interviewed in 2005;
- **Richard Ferreira**, the Director of Education Outreach, Harlem Congregations for Community Improvement, interviewed in 2006;
- **Cannon Frederick Williams**, Chairman of the Board at Harlem Congregations of Community Improvement, interviewed in 2006.

Activists:

I take a step back in this dissertation to examine the larger picture of AIDS discourse and the Black community in New York City and, specifically, Harlem. I

explore how homophobia within the Church influenced responses to AIDS. To that end, I interviewed a number of different people who worked in organizations that provided AIDS education to the Black community as well as those who are knowledgeable about the experiences of Blacks in the Church. I refer to these people as AIDS activists and they consisted of the following:

- **Kevin McGruder**, Former Executive Director of Gay Men of African Decent, and a Doctoral Candidate in history at the Graduate Center, interviewed in 2005;
- **Michael Elam**, Master of Theology and Ethics Student at the Union Theological Seminary and Researcher on sexuality in African cultures, interviewed in 2005;
- **Kenyon Farrow**, Communications and Public Education Coordinator, and author, interviewed in 2005;
- **Patricia Shelton**, Case manager and Activist for Gay Men's Health Crisis, interviewed in 2006;
- **Rev. Dr. Yorell Trumpet**, The New York City Department of Health and Mental Hygiene, interviewed in 2006.

Content Analysis:

I conducted an analysis of the material produced by The Balm in Gilead, and the material distributed by organizations such as Gay Men's Health Crisis, Harlem Congregations for Community Improvement, and materials created by Centers for Disease Control and Prevention. I also examined the types of materials distributed by churches during the Black Church Week of Prayer. As suggested by Neuendorf (2002), I focused both on the "manifest and latent meanings behind the characteristics of text or image or both, such as the message's construction, form, metaphors, argumentation structure, and choices [examining not only] *what* the message says [but also] *how* the message is presented" (Neuendorf 2002: 5).

I created codes for each piece of material (Krippendorff 2003; Neuendorf 2002), identifying where I obtained it, what type of material it was, as well as the themes, and

the message it conveyed. I focused on how AIDS was discussed by The Balm in relation to church teachings and values. I also examined how AIDS information was communicated to churches by other organizations and compared those representations to that of The Balm in Gilead's. I focused on the pictures displayed, the types of patterns that occurred, the words used, and how the overall material was presented (Neuendorf 2002). These codes were then categorized under larger themes and were analyzed along with my other findings (Neuendorf 2002)

Data Analysis:

My research does not test a preconceived research hypothesis, but explores how an organization interacts with a social institution. As a result, I used grounded theory to guide my data collection and analysis. Charmaz (2000) notes four ways in which grounded theory, as an exploratory method, assists the researcher to, "(a) study social and social psychological processes, (b) to direct data collection, (c) to manage data analysis, and (d) to develop an abstract theoretical framework that explains the studies process" (Charmaz 2000: 675). In 1967, Barney G. Glaser and Anselm L. Strauss provided guidelines and justifications for not only how best to conduct grounded theory but also how grounded theory can be best utilized. Grounded theory stresses the discovery of theory through research, not merely theory testing (Glaser and Strauss 1967/1999). As grounded theory and ethnographic research methods and analysis dictated, my data was analyzed at the same time that it was collected, and helped to guide how I continued to collect data (Charmaz 2000).

All of the data collected – field notes, interviews, and content analysis – received a line-by-line analysis and was coded based on themes or concepts (Charmaz 2000).

These themes included discussions of race, gender and sexuality, class, AIDS stigma, drug use, the production of facts, notions of identity, and material production. The data (interviews, field notes, and materials) were coded by hand, with different themes and events given a numerical code. Memos, or little comments used to explain quotes, were written based on the themes and codes and were selected for inclusion in the dissertation (Charmaz 2000).

After I coded these themes, similar in fashion to the data analysis that Pattillo-McCoy (2000) used in her ethnographic study, I also used applied sociological theory to explain the themes and behaviors which I noticed in my study. As I analyzed the data, the story that unfolded before me was of different understandings of AIDS and AIDS knowledge. I began to further focus on theories of the sociology of knowledge and the social construction of knowledge as they pertain to AIDS awareness. I conducted further examinations of the social constructions of health, illness, and AIDS, and these works (which will be discussed in more detail in proceeding chapters) along with my emerging data led me to develop theories on the different social constructions of AIDS as a social problem. It was then that I was able to analyze how Balm in Gilead reconstructs AIDS to be church appropriate, forming the basic thesis of this dissertation.

Chapter 3

Within the Rafters: The Black Church AIDS Movement

Introduction:

On May 8, 2006 *Time Magazine* released its special issue, "100: The Lives and Ideas of the World's Most Influential People" – their "list of the men and women whose power, talent or moral example is transforming our lives" (2006: 48). Among well-known leaders, entertainers, and humanitarians, such as Condoleezza Rice, Hilary Rodham Clinton, Bono, Bill and Melinda Gates, and Pope Benedict XVI, is Pernessa Seele. Under the heading "Heroes and Pioneers," and a page after an article about Elie Wiesel, is an article about Seele, her work with the Black Church, and the "high-level notice" (Gorman 2006: 68) that she had been receiving.

Seele and The Balm in Gilead have appeared in hundreds of articles in newspapers, magazines, and journals around the country. In the third decade of the AIDS epidemic, much focus has been placed on AIDS within the Black community. In both politics and in the media, very recently it appears as if a direct connection has been made between combating AIDS in the Black community and enlisting the aid of faith leaders to work directly in this campaign. For example, in February 2006, Seele was the special guest of First Lady Laura Bush during the President's State of the Union Address[20], where President George W. Bush spoke with great concern about the rates of AIDS in the

[20] As he mentioned throughout the Address, Bush advocated since he was governor of Texas for the collaboration of government and faith-based leadership in implementing community based social service programs. There is much to be said about this, and I will provide a more detailed discussion of his Faith- Based Initiatives in the conclusion of this dissertation.

Black community. As will be discussed in following chapters, newspapers, magazines, news programs, and documentaries have all made mention of the Black Church in combating AIDS in the Black community. In most of these discussions, Seele and The Balm in Gilead are mentioned. *Newsweek* quoted Seele in its May 15, 2006 special issue, "AIDS at 25," saying that the Black Church, "is the center of turning this crisis around" (Kalb and Murr 2006: 48). It appears as if Seele and The Balm have become synonymous with AIDS in the Black Church, prompting Gorman (2006) to write, "her efforts have led to a national movement to address public-health issues through communities of faith" (68).

The Balm in Gilead has re-defined AIDS from being a disease of sinners to a public health issue facing the Black Church and the larger Black community. In a strategic move, The Balm in Gilead capitalized on and helped to construct further the "Black Church's" reputation (Polletta and Jasper 2001; Gamson 1996) as an influential cultural organization[21] within the Black community. By evoking a sense of solidarity

[21] Culture, "consists of all learned behavior, all that is not instinctive and automatic. It includes material objects and artifacts created by people and non-material inventions such as religion and philosophy. Among culture's most important elements are language and other symbolic meaning systems, norms, taboos, rites, and rituals" (Blumberg 1987: 158). Swartz contends that, "culture includes beliefs, traditions, values, and language; it also mediates practices by connecting individuals and groups to institutionalized hierarchies" (1997). Blumberg (1987) argues that organizations have very distinct cultures that "are not formed totally new but grow out of the societies in which they originate and reproduce these societies in some manner (158). As an institution, the Black Church has culture that has, as mentioned in the introduction, been born out of the experience of Blacks in America. Sociologists and social thinkers – most notably Bourdieu, Levi-Strauss, and Foucault – all argue that culture is used to reinforce power relations (Swartz 1997).

It is important to note that in this dissertation I am not as interested in the "hegemonic effects" (During 1993) of the Black Church culture on the larger Black community as why AIDS was "ignored" among Blacks at the beginning of the epidemic. I am aware of the "symbolic power" – as Bourdieu (1979) would call it -- that the Black

among Black Churches, The Balm uses the Church as a cultural resource through which to "frame" (Edelman 1977) AIDS as a disease facing the Black community. The Balm in Gilead initiated a social movement among Black churches to address AIDS and encourage awareness, which, it hoped, in turn, would encourage the larger Black community to see AIDS as a disease plaguing its community.

This chapter serves two main purposes; the first is to provide an organizational history of The Balm in Gilead – a time line, so to speak – of its development as it fits in the larger historical context of African American AIDS discourse. The second purpose is to place the Balm's activities within the context of social movement theory, applying understandings of collective action to its campaign.

Social Movements:

There is an immense level of complexity to analyzing social movements. Mayer and Roth write: "the social movement theories we have today are rooted in a range of paradigms of social organization, leading to divergent assumptions about the nature of social conflict and social order" (1995: 229). They argue that American social movement theorists favor a more organizational approach, examining "strategic effectiveness, tangible goals and a (larger) share of the distributional pie" as opposed to examining why movements start and issues of identity these movements cultivate (Polletta and Jasper

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Church possesses within the Black community. As mentioned in the first chapter, the taboo issues associated with AIDS – i.e. drug use, sex – violated the cultural values of most Black churches. As I will address in more detail throughout this dissertation, these taboo issues, according to my respondents, prevented church leaders from focusing on AIDS at the beginning of the epidemic. I am interested in cultural understandings of AIDS within the Black Church, how my respondents perceive the Black Church's view of AIDS, and how this influenced AIDS discourse and the creation of church appropriate AIDS material within the Black Church.

2001; Gamson 1996; Mayer and Roth 1995: 299). Goodwin and Jasper (2003), however, offer a more traditional definition of a social movement as, "a collective, organized, sustained, and non-institutional challenge to authorities, powerholders, or cultural beliefs and practices" (3). The nature of social movements, and the ways in which scholars have studied them, have changed drastically throughout the years.

Though there have always been challenges to power, according to Tilly (2004), social movements – as we understand them today – began in late 18th century England as the power of the monarchy weakened and groups mobilized to make claims on newly developing governments (Tilly 2004: 9). Yet, it was the political upheavals of the "long 60s" (Edelman 2001: 285) that caused scholars to re-think collective action and movements. Prior to the 1960s, social movements were studied under the guise of "nonrational or irrational responses by alienated individuals to social strain and breakdown" (Gamson 1991: 37). This change encouraged scholars to focus more on identity as a mobilizing force within a movement (Edelman 2001). Civil rights movements emphasized the commonality individuals had within a group and built on this unified sense of a shared identity (Gamson 1995; Williams 1995; Hunt, Benford, and Snow 1994; Friedman and McAdam 1992; Melucci 1989; Swidler 1986). These movements inspired the creation of a "public collective identity" (Gamson 1995: 391).

Regardless of the nature of the movement, Charles Tilly (2004) contends that social movements:

> emerged from an innovative, consequential synthesis of three elements:
>
> 1. a sustained, organized public effort at making collective claims;
> 2. employment of combinations [of] the following forms of political action: creation of special-purpose associations and coalitions, public meetings, solemn

> processions, vigils, rallies, demonstrations, petition drives, statements to and in the public media, and pamphleteering; and
> 3. participants' concerted public representations of worthiness, unity, numbers, and commitment on the part of themselves and/or their constituencies. (3-4)

After the 1960s, divergent approaches to studying social movements began to develop. Scholars looked for ways to explain the collective action and claims groups were making upon not only the government but social institutions (Edelman 2001). As mentioned above, analysis of identity based movements has tended to focus "more on the 'why' than the 'how' of social movements" (Mayer and Roth 1995: 301). American scholars have criticized European-based paradigms for studying identity-based or new social movement (NSM) group mobilizations that developed in the mid-1970s (Edelman 2001) because of this scholarship lacked of focus on resource mobilization (RM) (Edelman 2001).

NSMs are considered, "new because their concerns no longer revolve around legal/political equality or economic demands, which used to be characteristic of the important movements in Western Europe's past. The fact that they are about lifestyles, cultural politics, identity and the politics of everyday life – and only secondarily interested in state policy or state power, is thus made out to be the shared and defining feature" (Mayer and Roth 1995: 304). Edelman (2001) argues that NSM theories have been used to describe the political upheaval of the "long 60s." Edelman (2001) explains, "Although the 'old' labor movement upheld class as the primary social cleavage, category of analysis, organizational principle, and political issue, the NSMs emerge out of the crisis of modernity and focus struggles over symbolic, informational, and cultural resources and rights to specificity and difference" (289). Yet, Joshua Gamson maintains that what ultimately makes NSMs "new" is "both disputed and unclear" (1991: 38).

During this same time, American scholars focused on the means by which social movements were organized. Resource mobilization (RM) theory argues for an understanding of the structural component of a movement (Mayer and Roth: 1995: 301). RM examines: "the construction of 'social movement industries' made up of 'social movement organizations,' regarded collective action mainly as interest group politics played out by socially connect groups rather than by the most disaffected" (Edelman 2001: 289). According to RM theory, actors make, "rational calculations… focusing on the varying constraints and opportunities in which they operate and the varying resources upon which they draw" (Gamson 1991: 37). As opposed to RMs, NSMs have witnessed the rallying of groups based on sexual orientation, ethnicity, gender, and various other aspects of their identity, emphasizing sameness[22] (Gamson 1991). It was the AIDS epidemic, however, that changed the nature of the NSM, introducing the notion of health as an aspect of identity and force for mobilization.

As I will describe in more detail in the following chapter, national and cultural responses to the AIDS epidemic created a sense of "sameness" and a common shared identity among those infected which aided in early AIDS activism such as the efforts of ACT-UP[23] and other AIDS activist groups (Chambre 2006; Gamson 1991). Gamson

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[22] In a sense, the primary difference between resource mobilization and identity politics is similar to Weber's focus on instrumental versus normative rationality. Instrumental rationality (*Zweckrationality*), or the "problem-solving rationality that identifies the means for achieving some given end" (Jerolmack and Porpora 2004: 140) is similar to the goals in RSM movements. Whereas the drive behind normative rational (*Wertrationality*) decision-making is much more personal and motivated by some type of "moral or ideal" (Jerolmack and Porpora 2004: 141), like that of identity based movements.

[23] Larry Kramer founded ACT UP, or the AIDS Coalition to Unleash Power, in 1987. Kramer is a well-known AIDS activist and a playwright who, during a speech at the

(1991) argues that the AIDS activist movement is the perfect example of a NSM. It had, "a (broadly) middle-class membership and a mix of instrumental, expressive, and identity-oriented activities. Rather than exclusively orienting itself toward material distribution, ACT UP uses and targets cultural resources as well" (Gamson 1991: 39). Early AIDS activists not only influenced policy and funding surrounding HIV/AIDS testing but also influenced other social movements in health and the ways in which scholars think about health social movements (HSMs) (Brown and Zavestoski 2005).

Phil Brown and Stephen Zavestoski (2004):

> define HSMs (health social movement) as collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organizations, supporters, networks of co-operation and media. HSMs make many challenges to political power, professional authority and personal and collective identity. These movements address (a) access to, or provision of, health-care services; (b) disease, illness experience, disability and contested illness; and (c) health inequality and inequality based on race, ethnicity, gender, class and/or sexuality. (1)

Emily S. Kolker argues (2005) that HSMs have drastically changed within the past 20 years. Kolker points out, "Previously HSMs had focused primarily on problems of patient care, including access to health care and health services" (137). More recently, those who participated in HSMs have focused more on resources allocated for health services and education. The social concerns associated with AIDS – homosexuality, intravenous drug use, promiscuity, death, and sin – prevented many organizations, including governmental institutions (Brown, Waszak, and Childers 1989; Shilts 1987),

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Lesbian and Gay Community Center in New York City, argued that those involved in the Gay Rights Movement should mobilize to demand policy and better treatment for those with AIDS. Within a week of this speech, hundreds of people attended a meeting, marking the birth of ACT UP. With "Silence = Death" as one of its many slogans, ACT UP effectively used media attention tactics to champion its causes. Eventually, ACT UP organized chapters in Boston, Chicago, Los Angeles, and other cities.

schools (Starkman and Rajani 2002; Freedman 2006), churches (Weatherford and Weatherford 1999; Shelp and Sunderland 1992), and even the health care industry (Brown, Waszak, and Childers 1989; Shilts 1987) from adequately responding to the AIDS epidemic and sanctioning the education and resources necessary to prevent the spread of HIV. Currently, HSMs, Kolker (2005) argues, focus on framing illnesses to resonate with desired audiences. Kolker (2005) writes: "HSM activists must, in Mills's terms (1959), redefine disease from a personal trouble to a public issue. To do so, they draw upon important cultural resources" (137).

Kolker builds upon Snow, Rochford, Worden and Benford's (1986) article which attempts to convince social movement scholars to analyze the how "frames" ignite a movement and then apply those insights to social movement theory. Social movement theorists argue the importance of frames (Kolker 2005; Benford and Snow 2000; Tarrow 1998; Williams 1995) or "interpretive schemas" in "mobilizing collection action" (Kolker 2005: 138). Williams contends: "ideological 'frames'… organize experience, motivate action, and justify the movement's agenda" (Williams 1995: 125).

Though I provide a more detailed discussion of Goffman's *Frame Analysis* in the fifth chapter, it bears brief mentioning here. Goffman writes that frames are, "principles of organization which govern events – at least social ones – and our subjective involvement in them" (1974: 10). Although Goffman (1974) first discussed the concept of frames as the lens through which people view the world, the term "framing" as used in social movement theory has a slightly different connotation (Benford and Snow 2000). Benford and Snow (2000) argue that framing is the process by which social movement activists and/or organizations construct symbols and meaning that resonate with a

population in order to generate a social movement. They argue that prior works on social movements, "neglect the process of grievance interpretation; they suggest a static view of participation; and they tend to over-generalize participation-related processes" (Snow, et al. 1986: 465). Within the past 20 years or so, social movement scholars have paid increased attention to the use of "framing processes" and the use of culturally resonant themes within social movements (Benford and Snow 2000: 612).

In her chapter tracing the social movement for breast cancer funding, Kolker (2005) stresses the importance of culturally resonant themes in promoting this cause. She claims, "breast cancer funding activists used culturally resonant frames to persuade audiences and to redefine breast cancer from a private problem of individual women to a major public health problem worthy of increased federal funding" (2005: 137). Between 1990 and 1993, she argues, breast cancer activists made significant advances in breast cancer funding and in re-defining and reframing beast cancer as not a personal woman's issue – something of which to be ashamed – but as a large scale social issue worthy of a federal response. Kolker points out, "social movement actors utilize cultural ideologies in their framing activities to construct persuasive and culturally resonant frames and redefine social conditions" (2005: 138). Again, she maintains that breast cancer was framed to argue that breast cancer was costing the country billions in health costs and lost productivity. To achieve their goals, activists relied on three "culturally resonant frames," which consisted of: "breast cancer as an epidemic, beast cancer as a problem of gender equity, and breast cancer as a threat to families" (Kolker 2005: 142).

One of the tactics used by early AIDS activists in encouraging increased funds and better policy was to "frame" AIDS in such a way as to take the focus away from the

modes of transmission and to emphasize the disease itself. Susan Chambre writes that the AIDS community, "stressed the uniqueness of the disease and the need for distinct policies and funding to fight the epidemic. A master frame in its ideology was that spending money would save lives, which resonated with a central feature of American political culture, the fact that politicians and the public are indeed highly committed to spending money to save lives" (2006: 4).

I contend, in similar fashion to the breast cancer funding activists of the early 90s and early AIDS activists, that Pernessa Seele, the founder and CEO of The Balm in Gilead, organized a social movement and made a claim among Black Churches that redefined AIDS as a social problem facing the Black Church. Spector and Kitsuse (1987) define a social problem as "the activities of individuals or groups making assertions of grievances and claims with respect to some putative conditions. The emergence of a social problem is contingent upon the organization of activities asserting the need for eradicating, ameliorating, or otherwise changing some condition" (75-76). Importantly, Nisbet (1971) notes that a social problem only exists when it has become "defined" (2) as such. As I will show in the next section, Black churches were aware of the devastation AIDS inflicted on the Black community, but they really did not see it as their problem until it was framed as such by Seele[24], who served as both the Black Church AIDS movement's charismatic leader and moral entrepreneur (Becker 1963). Seele constructed AIDS as a social issue facing the Black community, emphasizing the morality of the

[24] Though I touch upon this further in this dissertation, it is important to note that it was not only Seele and The Balm that encouraged churches to address AIDS. Parishioners, community leaders, and groups also encouraged their pastors to provide awareness, education, and support. However, I do attribute the large-scale mobilization of Black churches in addressing AIDS to be the work of Seele and The Balm.

Black Church and used this morality as a "culturally resonant frame" (Kolker 2005: 141) to create a moral panic (Good and Ben-Yehuda 1994a, 1994b). This reframing occurred among Black churches through an emphasis on AIDS not a disease of the "outsider" (Becker 1963) but as a disease having a direct impact on the Black Church.

Leadership:

Max Weber (1958) argued that leadership comes in different forms – traditional, rational, and charismatic – though he discusses these forms of leadership primarily in terms of political power and authority. He states that there exists, "the authority of the extraordinary and personal *gift of grace* (charisma), the absolutely personal devotion and personal confidence in revelation, heroism, or other qualities of individual leadership" (Weber: 1958: 79), that would describe the qualities often found in social movement leadership. A charismatic leader, by virtue of her charm, authority, and leadership skills is trusted to organize and lead a movement or political action, for "men do not obey him [or her] by virtue of tradition or statue, but because they believe in him [or her]" (Weber 1958: 79). There are different types of charismatic leaders, for example, the "magician and the prophet" or the "elected war lord, the gang leader" (Weber 1958: 80). Though Weber applied this taxonomy to religious leadership, the type that is of interest to my research is that of the magician or the prophet – an individual, who, through her "magical charisma" (1958: 327) is able to secure a following with the "mission, or the savior quality of their personalities" (1958: 327).

Davis, et al. (2005) contend that early social movement theorists believed that "charisma and rhetoric, not formal-legal authority… induce[d] participation in their followers" (Davis, McAdam, Scott, and Zald 2005: xiii). Social movements often require

a spokesperson to get the movement active. Many of these leaders possess a magical, prophet-like quality that their followers believe will lead them in their quest for equality, better treatment, or the means to overcome whatever social ill may be afflicting them (Davis, et al. 2005). Though often there is not a single leader who spearheads a movement, it sometimes becomes necessary to attach a face to these movements, a single person with the charisma to attract sympathy and instill trust not only from followers but also from opponents. For example, the abolitionist movement had Frederick Douglass, the suffrage movement had Susan B. Anthony, the civil rights movement had Martin Luther King Jr., the women's rights movement had Gloria Steinem, and the AIDS movement had Larry Kramer. These movements all had (and have) figureheads and spokespeople to keep the movement going, as has been the case with Pernessa Seele and the Black Church AIDS movement.

Born 51 years ago and raised in the all-Black town of Lincolnville, South Carolina, Seele moved to New York in 1979. With a master's degree in immunology, Seele went to work for Rockefeller University conducting malaria research. She then took a position at Sloan Kettering Memorial Hospital to do cancer research, and then worked as a consultant, developing AIDS education programs before working as an administrator at Harlem Hospital's AIDS Initiative Program. Goode and Ben-Yehuda (1994b) argue social issues sometimes "are discovered as problems by a single crusader who, initially, had little or no access to organizational resources" (92). Though rare, they contend that usually "organizational representatives of a group or cause" bring these social issues to light (92). Seele was that rare exception.

After working in Harlem Hospital for only three days, Seele stated, "my function took me on the wards, and I had to actually go and see people in beds dying of AIDS. I was really struck by the lack of spiritual support – not one pastor [or] clergy at the bedsides of these dying individuals" (Seele, interviewed in Gilbert 2003: 154). Yet this was in no way peculiar to Harlem Hospital or to Black clergy. Canon Frederick Williams of the Church of the Intercession in Harlem spoke of a parishioner of his, who as a nurse in the hospital on Roosevelt Island in the early 80s witnessed "the warehousing of all of these [AIDS] patients. They were basically putting them up there and leaving them on the top floor to die. Nobody would go up there, none of the staff, the doctors only made infrequent visits up there" (Williams). Black religious leaders participated in similar behavior. Within the Black community, there is an expectation for clergy to minister to, and congregants to visit, the sick and dying (Jumanne 2005; Peterson, Atwood, and Yates 2002 Weatherford and Weatherford 1999; Shelp and Sunderland 1992). Seele and the nurse in Canon Williams' congregation were disturbed that the Black Church community was not visiting these people just because they had AIDS. Darlene Cheek noted, "Their membership were in the hospital and pastors weren't visiting them" (Cheek). Seele was surprised that these leaders could not see past the modes of transmission to see the illness itself and simply pray for those infected.

As a long-time member of St. Mark's United Methodist Church in Harlem, Seele believes that the Black Church plays a pivotal role for many Blacks in the community. In fact, all of my respondents emphasized the importance of the Church in the Black community. For example, Debra Levine of the Black Leadership Commission on AIDS states: "[The Church is] really the cornerstone. It is all important" (Levine). The Church

plays a role in health and healing within the Black community and, therefore, Seele was shocked by the lack of support that she noticed from the Church. Seele contended: "There were 352 churches surrounding Harlem Hospital in the center of the community, the churches were so distant" (Seele, interviewed in Gilbert 2003: 154). This was especially shocking in Harlem where, as mentioned in Chapter One, during the Great Migration, the Black Church served as an extended family for many Blacks who left the South and ventured North alone (Lincoln and Mamiya 1990). Consequently, many churches expanded, and the role of the Church in the lives of Blacks, especially in the urban North, increased. Rev. Ware of The Balm in Gilead believes: "It still has a very powerful, pivotal role, because the power is there in that they affect the lives of, I think, more people than any other organization and community" (Ware).

Understanding this "pivotal role," Seele got an idea. She elaborates: "I was born with the gift of ideas. Some people are born with the gift of piano. Some people can see a piano and start playing. Some people can play the saxophone. Some people can just play chess. I was born with the gift of ideas. Ideas – that's my gift from God" (Seele). Seele, "had the idea to mobilize the religious community of Harlem, not just the Christian churches but the entire religious community" (Seele, Interviewed in Gilbert 2003: 154). She states: "I wanted people to become more responsive to the needs of people living with HIV, and to really open up their hearts and minds and support people living with HIV" (Seele).

Modeled after Southern Christian revivals, the Harlem Week of Prayer was based on "the idea of… motivating people to come together around prayer" (Seele, interviewed in Gilbert 2003: 155). Healing became the key concept, for it was the, "healing of the

attitudes… you are not actually saying you are healing somebody, but you can heal the attitude of the Church towards someone who's infected or affected… healing comes in different forms" (Ware). Seele reached out to churches all over Harlem. She began with the help of a chaplain at Harlem Hospital and then approached Harlem Congregations for Community Improvement (HCCI). Seele remembers:

> Preston Washington Sr. was the president [of HCCI] and he was also the pastor of Memorial Baptist Church. So, I went to Memorial Baptist Church one Sunday and I sat there, and sat there, and sat there, and sat there, and sat there, and after church there was a line from here to California to wait to see Pastor Washington… When I got to him I said "Dr. Washington, I am Pernessa Seele, and we are having a Harlem Week of Prayer for the Healing of AIDS. We, of course was we and thee. I didn't have nobody, and he said come to the next meeting of HCCI and I went and I sat there… and I got my little two minutes to say something and I said something and that was that. (Seele)

Fifty-two pastors attended that meeting, and, according to Seele, the endorsement of well-known preachers and of HCCI was great but ultimately:

> it was the people in the pew. It was the community folks who attend those churches that really kind of made the movement happen. It was Ms. Mary who came to the grassroots meetings and who really got excited about the coming together of these religions to address HIV. And it was those people in the pew who went back to their pastor. Now, so there were different things going on. I go and I'm at a meeting, at the hierarchal meeting, I get my nod, that's great. But often times a lot of people come in and they get their needs, but it was the commitment of the people from the Church, from the individual, the pew. It was the people in the pew who had heard about what was going on, who got excited about this community mobilization effort, and who really went back to their pastors and said "Pastor, this is something that we really got to support." " Pastor, we got to go to this." It was the excitement of the pew that really brought those leaders, out, when we really did the event. (Seele)

It was during this initial meeting at HCCI that Seele first, officially, made the "claim"[25] (Spector and Kitsuse 1987) that Black Church members and leaders need to

[25] Spector and Kitsuse (1987) argue that claims-making is "a demand made by one part to another that something be done about some putative condition. A claim implies that the claimant has a right at least to be heard, if not to receive satisfaction" (78).

address HIV/AIDS. As Tilly (2004: 4) contends, it was, indeed the "commitment" of both Seele, and, importantly, "unity, numbers, and commitment on the part [of] their constituencies," that gave this movement life. As word spread throughout Harlem, both church leaders and members mobilized and committed to hosting AIDS events at their churches; and it took about two months to organize the first Week of Prayer.

As idealistic as it may sound, Seele was quite strategic in mobilizing these religious leaders. She emphasized the role of the Church in the Black community, and especially within Harlem. She argued that something was wrong, that churches and other religious institutions should acknowledge and pray for those with HIV/AIDS within Harlem. Pernessa Seele created a "moral panic" – in the truest sense of the word – among Black religious institutions in Harlem.

According to Erich Goode and Nachman Ben-Yehuda (1994b), "in a moral panic, a group or category engages, or is said to engage, in unacceptable, immoral behavior, presumably causes or is responsible for serious harmful consequences, and is therefore seen as a threat to the well-being, basic values and interests of the society presumably threatened by them" (31). Seele constructed AIDS as an issue for the Black Church and that ignited a moral panic among Black religious leaders, encouraging them to address AIDS. Moral panics occur when an individual, quite often a "moral entrepreneur[26]" (Yurtsever 2003; Becker 1963) points out a "wrong" in society with an attempt to rally groups, organizations, institutions, or agencies to fix it (Thompson 1998; Goode and Ben-

[26] I am aware of the difference between a movement entrepreneur and a moral entrepreneur in that, as Edelman contends, "movement entrepreneurs had the task of mobilizing resources and channeling discontent into organizational forms" (2001: 289). Moral entrepreneurs are more focused on the "values system" (Yurtsever 2003: 2) of their target audience.

Yehuda 1994a, 1994b). Gulcimen Yurtsever (2003) states: "Moral entrepreneurs are activists who attempt to persuade others to adhere to a particular value system. They are important individuals because of the extent to which they can, or do, anticipate potential moral threats to society, suggest clear and acceptable solutions for moral issues, create public awareness, mobilize power and because of the scope, type and quality of resistance they encounter" (2). Goode and Ben-Yehuda point out that though the concept of a moral panic "is fairly recent, the concrete manifestations of moral panics have been described and analyzed for some time in a more or less implicit fashion" (1994b: 11). Goode and Ben-Yehuda argue that a social movement is a "manifestation of the moral panic" (1994b: 122).

Often, when moral panics are described, they are done so in the context of rock 'n roll music, drug use, crime, etc. Religious institutions are rarely the cause of a moral panic. However, Seele constructed just that among Black religious institutions in Harlem. I contend that Seele created a "panic" by emphasizing the "moral" duty of Harlem religious institutions to address AIDS. She pointed out to church leaders that their lack of action, their lack of prayer, was causing harm to the community and those suffering from AIDS.

Terms like claim-makers, moral entrepreneurs, "moral crusader" (Becker 1963: 148), and charismatic leader all properly describe Seele. She argued to church leaders that not only was addressing AIDS the right thing to do, but it was also "good" for the Church and good for the community. She stated, "What I wanted to happen was, I really was focused on Harlem and I wanted people to become more responsive to the needs of people living with HIV, and to open up their hearts and minds and support people living

with HIV. That was my very naive desire in the beginning" (Seele). Yet, it was this "naive desire" that began a social movement.

The Beginning of a Movement:

During this time, Seele was most concerned with the moral obligations of the Black Church to address AIDS. She wanted religious leaders to understand that, regardless of the modes of transmission, Harlem religious institutions were obligated to address AIDS. Based on this premise, the "kick-off to the first Week of Prayer" (Seele) was a march around Harlem Hospital. In a 2003 interview with Gilbert, Seele noted, "And of course we had to do the drama thing, you know cultural dramatics, with everyone walking around Harlem Hospital in their religious garb – Christians, Africans, Muslims, carrying pyramids and religious and universal symbols and such. All these Black people with such different religious affiliations coming together… it was exciting!" (Seele, interviewed in Gilbert 2003: 155). The first march around Harlem Hospital followed by the Harlem Week of Prayer, "was a phenomenon… the first one was the coming together of the five faith religions that had never come together before – it was just an excitement in the air" (Seele). The following year, after being "caught up in the success of it" (Seele), Seele decided to do a second Week of Prayer, thus sustaining the movement among the target audience (Tilly 2004). "The second one was exciting too, but people knew what they were gonna do" (Seele). Remembering the second march around Harlem Hospital in 1990, Canon Williams stated, "preachers in their robes marching was not unusual, we often did that… What was unusual was, it was cold as hell. And there we were out there, trying to sing these songs and you know, in the middle

of the winter and stopping to pray every now and then. Well, that wasn't unusual in Harlem" (Williams).

The marches around Harlem Hospital displayed the qualities that Charles Tilly (2004) describes in his analysis of social movements. Tilly explains worthiness as being a, "sober demeanor; neat clothing; presence of clergy, dignitaries, and mothers with children" (4). As Canon Williams describes above, these marches had church and religious leaders wearing their robes singing and chanting, displaying, "Unity: matching badges, headbands, banners, or costumes; marching in ranks; singing and chanting" (Tilly 2004: 4). There were over 50 religious leaders at the first march and well over that at the second march, marching around the hospital and into the street, again, fulfilling "numbers; headcounts… messages from constituents, filling the streets" (Tilly 2004: 4). Their commitment was evident as described in Cannon William's account of the march, they "brav[ed] bad weather" and displayed, their "resistance to repression; ostentatious sacrifice, subscription, and/or benefaction" (Tilly 2004: 4).

Shortly after the second Week of Prayer, Seele left Harlem Hospital and took a job at HCCI, as the vice president for social services, where she was promoted to general health education and awareness among Harlem churches. According to her, "As I moved into the process, I realized how much information people did not have" (Seele), and it was during this time that she shifted her focus from just AIDS awareness to AIDS education. At HCCI, she "brought that sense of, if you gonna do community development, you're really concerned about doing more than just building houses or renovating houses, you've got to have this health component" (Williams). As this focus on health increased, the success of the Week of Prayer spread nationally.

Seele "was invited to speak at what was then called the National Minority AIDS Conference on Faith-Based Issues in California" (Seele, interviewed in Gilbert 2003: 154). Soon,

> People were sending letters to the Week of Prayer, wanting training and technical assistance from the Week of Prayer, and it was clear that there was a need, there was an ongoing need. The Week of Prayer had become this launch pad to get churches involved, but they needed ongoing training, needed ongoing support. And the Week of Prayer was not that. The Week of Prayer was an annual event. So, I said "ok – making it up again – let's put something around it. Let's put an organization around it." And we did that. (Seele)

Therefore, in 1993, while working at HCCI, Seele organized The Balm in Gilead. She realized that an organization needed to exist to sustain the momentum of church involvement in organizing around AIDS because, "if [movements] are to be sustained for any length of time, [they] require some form of organization: leadership, administrative structure, incentives for participation, and a means for acquiring resources and support" (McAdam and Scott 2005: 6). She had the benefit of lawyers working pro bono to help her obtain 501-C(3) non-profit status, but there was still no name for the organization.

Seele recalls that after riding her stationary bike in her Harlem apartment, she noticed Sarah Lawurence-Lightfoot's *Balm in Gilead* on her bookshelf and "something" told her to name the organization "The Balm in Gilead." Though she was skeptical whether or not people would be able to understand that The Balm in Gilead was an organization that helped Black Churches address issues of HIV/AIDS, she chose the name anyway. Despite being raised in the Church, she was unaware of its religious significance. The old hymn, "There is a Balm in Gilead" has been recorded by artists such as Jessie Norman, Mahalia Jackson, Mary Wilson, and Nina Simone for generations. The phrase "balm in Gilead" is from Jeremiah 8:22, which asks "is there no balm in

Gilead? Is there no balm in Gilead? Is there no physician there? Why then has the health of my poor people not been restored?" With the combination of the song and the biblical reference, "churches knew exactly what I was talking about, they were like 'yeah, there is a Balm in Gilead,' you know, they started singing, and we had a song. Again, I just made it up… There was no rocket science, there was no committee, there was no strategic plan. I just made it up and it worked!" (Seele).

Seele left HCCI and opened The Balm with a staff of one full time employee (Darlene Cheek, who worked as an office manager), a part time bookkeeper, and volunteer staff member Douglas Parker. The Balm moved to its current location on 42nd St. and Broadway, but during that time, The Balm was housed in two small offices on the 13th floor. Balm employees began with mailings to promote the Black Church Week of Prayer the Black Leadership Conference at Howard University to churches all over the U.S. Though she had included educational information in her work with churches for the past two years, with the organizational development of The Balm in Gilead, Seele officially shifted the focus from simply AIDS awareness, prayer, and tolerance to education. Seele found that the Black Church was the ideal place for reaching out to the Black community because, as Latrice Wactor believes, the Church allows Blacks "to hear the message [that] they may not hear in a traditional manner." Seele and the Balm in Gilead staff felt that it was the ideal venue for health promotion.

Darlene Cheek, the original office manager, explains:

> Those sharecroppers and slaves who were nothing from Monday through Friday, took a bath on Saturday and on Sunday was Deacon So and So and Reverend Somebody. And on Monday they were still Joe and Sam, and Sarah and Sue. So everything pulled into the Church, everything came into the Church. So if you wanted to know who was sick in the community, you went to the Church. If you wanted to get better in the community, if Sister Sam was trying to treat her

> grandson who had the croup [cough], well, somebody in the Church knew how to handle the croup. So just go to the Church and find out who. Somebody's got a remedy for that! So the remedies all came into the Church. The remedies all came in the Church and that's what we went back to, the remedies in the Church. So if you can get the information in the Church, the community will receive it…. So, if the Church is addressing health issues, you have a better possibility of it being heard and received, because I'm in the Church and I know it, so I'm going to tell somebody that I know about it, and they're going to tell somebody else, and so on and so on, and that's how it gets out.

According to Tonya Perry, Assistant Professor of Social Work at Fordham University and the author of a number of Balm in Gilead publications, "Faith institutions are really an ideal kind of mechanism or vehicle for getting the word out, because faith is such a crucial, critical part of our lives, as people of African ancestry. So I think churches… are ideal mechanisms for what was happening" (Perry). But getting churches onboard was challenging. Cheek maintains, "It was a long process. It was getting churches to acknowledge that they are dealing with a disease. Getting churches to then say, we can work together to prevent this disease. It was a long process and that's still long. We still have some churches that will not, under any circumstance, talk about HIV and AIDS. They're still dealing with it, but they won't talk about it."

Seeing the potential for AIDS education on a national level, in 1995 the CDC provided pilot study funding to the Balm in Gilead with the help of the Institute for Minority Health Research, Rollins School of Public Health, Emory University, San Francisco's The Ark of Refuge, and other smaller community based organizations to replicate the Week of Prayer in seven U.S. cities[27]. With this funding, Seele turned her focus to a more national campaign. Across the country, she encouraged Black churches to host at least one AIDS specific event, and, more important, she urged pastors to deliver

[27] These cities were: in Macon and Atlanta, GA; Kansas City, MO; Cleveland, OH; Raleigh-Durham, NC; Albuquerque, NM; and Nashville, TN.

Sunday sermons to address AIDS. Understanding the importance of this initiative, Wactor points out that a pastor speaking on AIDS from the pulpit helps to "take away some of the stigma around HIV and AIDS." The Balm worked with a number of different religious institutions but kept its focus on Black religious institutions. It was in 1996 that the Harlem Week of Prayer for the Healing of AIDS became The Black Church Week of Prayer for the Healing of AIDS, though, this transition was not an easy one.

As mentioned above, Seele mobilized Harlem *religious institutions*, not just Black Protestant denominations or the Black Church, to address AIDS. This was no easy task, though significantly less complicated then mobilizing Black religious institutions across the United States. For one, Harlem is known for its religious institutions (Hickman 2001). Cynthia Hickman contends that Harlem religious institutions, "play[ed] a pivotal role in the establishment of Harlem as the 'Negro Mecca' during its renaissance in the 1920s" (2001: xi). Hickman also argues, as mentioned earlier, that Harlem is "perhaps, the most 'churched' community in the world" (2001: xi). With so many churches in such close proximity, as well as the "umbrella" organization (of sorts) – HCCI—it was easier for Seele to approach Harlem religious institutions to address AIDS. Regardless of the denomination, she argued, they were united with one goal – prayer. Also, geographically speaking, Harlem is compact. It is easy to create a sense of "community" with a common goal in a neighborhood comprised of about six square miles. In addition, the rates of HIV/AIDS among Blacks were always astronomical in Harlem as compared to the rest of the country. In order to expand the "movement" and make AIDS an issue facing the

Black Church as a national Black cultural institution[28], Seele had shifted the focus of the moral panic of Harlem congregations to an issue facing the larger Black community.

The Balm in Gilead:

Currently, The Balm in Gilead organizes a number of programs in addition to the Week of Prayer (years of implementation in parentheses):

- The Faith-Based HIV/AIDS National Technical Assistance Center (1996)
- The Black Church HIV/AIDS Training Institute (1999)
- Our Church Lights the Way HIV/AIDS Testing Campaign (2000)
- The African HIV/AIDS Faith Institute (2002)
- The Intimate Sessions for Informed Sexuality, or ISIS, Initiative (2005)
- The Denominational Leadership Initiative (2006)

Just as The Balm has grown, so too has its staff. The Balm originally consisted of four employees, and has currently grown to 14[29], eleven of whom are women. All Balm employees are Black, including African Americans, West Indians, and Africans. The composition of the staff is not unlike that of a typical Black Church, with the similar leadership role of the Black women at The Balm in Gilead mimicking the Black Church – a predominately female institution (Krause, Ellison, and Marcum 2002 ; Ellison and Sherkat 1995): "Black women run the churches, quiet as it's kept. The men may be in front, [but] the Black women run the churches" (Williams). In fact, being a woman may

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[28] Organizational sociology argues that organizations have particular identities. This identity, "affects not only how an organization defines itself, but also how strategic issues and problems, including the definition of firm capabilities and resources, are defined and resolved" (Glynn 2000: 286). The Black Church is more than just an organization, it is also a cultural institution. Glynn (2000) argues, "Most cultural institutions have identities composed of contradictory elements because they contain actors within the organization who come from different professions; as result, different groups of actors cherish and promote different aspects of the organization's identity" (285).

[29] Again, I stress that many things have changed since I wrote this piece. The Balm's staff has shrunk considerably with their move to Richmond, VA. A majority of the staff members that I worked alongside have chosen not to move to Richmond, and, as of November, 2006, Seele is hiring a new staff to rebuild the organization.

have helped Seele promote AIDS to the Black Church. Canon Williams notes, "I think her gender helped… I don't think the pastors were threatened by her because she's a woman. I think if she had been a man on this issue, it would have been more difficult because in the minds of a lot of people, AIDS is a gay issue. So, if you're a Black male involved in this issue then you must be gay, or there's that doubt." While not restricted to communities of color, women tend to take on caregiving roles; though there were many notable exceptions during the AIDS epidemic in which gay men cared for their ailing partners, friends, and community members, the majority of caregivers during the AIDS crisis were women (Cohen 1999).

In addition to being female, all of the employees I interviewed identified as Christian, and eight were ministers. Religion is a major part of the Balm work environment. Employees sang gospel songs when they are not being played on the radio, they would say "Blessed Be" at the end of phone calls, and a large wooden cross greets you when you walk in the front door. The spirituality of the staff was very apparent when, within my first couple of weeks at The Balm, Seele bought the staff lunch to thank us for the hard work. The following excerpt was taken from my field notes describing the event:

> *When the food arrived, it was immediately brought to the kitchen. Pernessa [Seele] then called the staff and volunteers together. She asked us to hold hands and before she blessed the food, Pernessa thanked all of the staff and volunteers for the hard work we all put in during the Week of Prayer. She also apologized that she couldn't afford to take us out to the Ritz for dinner, but that this was the best she could do. She then discussed her impending trip to Africa to check on the African Initiative programs. When she returns, the staff will then begin work on the new initiative - The ISIS initiative - dealing with cervical cancer and HPV. We bowed our hands in prayer. Pernessa blessed the food, her staff, and all the churches participating in the Black Church Week of Prayer, along with those suffering with HIV and AIDS. After the prayer, and a collective, 'Amen,' the staff*

> *spontaneously sang, "There is a Balm in Gilead." – Field Notes, Thursday, March 3, 2005*

Though we were not always rewarded with free lunches, there was often prayer in the office. This spirituality not only greatly influenced the work of the staff and volunteers at The Balm, but also its ability to relate to its "consumers." Not only does this provide a level of "sensitivity," but there is also an understanding of how the Black Church "works" – the protocol and rankings, songs, and rituals –that resonates with the Church. For example, Tonya Perry has written several pieces for The Balm, and she cites her own spirituality and beliefs as inspirations. As a Christian, Dr. Perry stated that there was, "a certain sensitivity that I wouldn't have otherwise and understanding the role of faith in my life, and what I know about the Black Church… I guess there's a certain sensitivity there" (Perry). Dr. Perry goes on to state that is why, "they have on board… people who have had religious background and [these people] have been more involved in actual content development" (Perry). She goes on to state:

> You know that faith is the center of what we do. The messages against stigma… and organizational principles that guide our work need to be reflected in everything we do, including the articles or whatever it is that we produce and so with the theological document, the presence of those principles needs to be reflected. Once they were, it was something that more reflected us. (Perry)

The Balm Today:

With the help and encouragement of The Balm, the Black Church as an institution began to address HIV. Angela Griffin, ministry leader of Berean Baptist Church's AIDS ministry in Brooklyn, believes most of these churches would not have done so without the guidance of The Balm:

> No, I don't think [the Church] would have [addressed HIV] on their own. I think that The Balm in Gilead definitely is instrumental. They have very good materials, and just the awareness, I think they give churches the freedom to come

> out and say, 'We're going to deal with this. We're going to talk about this. We're not going to sit back and act like it doesn't need addressing because our people are dying.' So, I mean they definitely brought it to the forefront.

A number of other religious leaders agree that The Balm in Gilead's mere existence showed that the Black Church was an appropriate venue for AIDS dialogue (though this dialogue most often consisted of prayer and AIDS awareness). For example, while attending The Balm's "Women of the Bible Addressing HIV/AIDS: The 16th Annual Black Church Week of Prayer for the Healing of AIDS," a male minister spoke to the AIDS stigma and stated: "As Jesus was crucified, [we] will be able to see a new insight through AIDS [God will] direct people's eyes to the mysterious lesson that God is giving because [The Balm is] qualified to show us" (Field Notes, Monday, March 7, 2005).

Those charged in spreading information within The Balm used spirituality and even their "influence as a clergy" (Mugarura) to reach churches. For example, Rev. Ware explains, "some of the ministers at that time [late 1990s] thought that [Seele] was a little radical and having a minister on board would <laughing> kind of ease that out." Though Darlene Cheek believed what ultimately worked best was:

> our constant presence, and our constant information giving and sending. Our constantly having different vehicles for people and venues that people could relate to. Our constantly being there to pick up the phone and… get someone to at least listen to whatever they're going through… That's when we became established, because they could say, 'well, I know that if you call The Balm in Gilead you can get so and so or if you call The Balm in Gilead they'll listen. Then they saw us, so we went to different venues, we went to different conferences, we did tabling in different situations and different areas. They were able to see us and know that they could talk to us and they could look at the materials and see what we had available. We became consistent. We constantly stayed in the community, consistently stayed out there. Our name was consistently put out there. (Cheek)

Rev. Yoreel Trumpet of the New York Department of Health agrees, believing that The Balm in Gilead "was finally a voice from the faith community – a voice of the faith. The faith person saying that… HIV and AIDS can be couched in the word of God." The Balm in Gilead became associated with HIV and AIDS awareness within the Black Church, and importantly, as mentioned above, AIDS became not only an acceptable topic for the Black Church, but in some communities, church-sponsored AIDS ministries became the norm. Canon Williams contends, "In Harlem, I can't say that across the board, now in America, but in Harlem, primarily from the seeds planed by Pernessa Seele and The Balm in Gilead through HCCI, the religious communities are, for all intents and purposes, 100% on board." This support leads Seele to maintain that, "The Balm [has become] a respected, recognized organization. The Church trusts The Balm in Gilead. We have been around for 17 years. Longevity brings respect" (Seele). This longevity and respect has manifested itself in a number of different ways, one being the transnational religious Black AIDS movement The Balm is working to create by assisting churches and other religious institutions in the Caribbean and various African nations in creating AIDS awareness programs.

The Black Church AIDS movement started by Seele and perpetuated by The Balm in Gilead has taken on a life of its own. Seele states, "Who knew, who the hell knew that I would be over the dern magazines <laughing> who knew that [I would be] on the front page of *Time Magazine*. Who knew? It's interesting." It is not just *Time Magazine* and *Newsweek*, but as stated above, she and the work of The Balm in Gilead have appeared in hundreds of newspapers and magazines. In fact, in 2005, *Essence Magazine* named her – along with 34 other activists, scholars, business leaders, and

entertainers –one of the 35 most beautiful women in the world. Susan L. Taylor, *Essence Magazine's* Editorial Director believes, "It's not what you look like; it's what you project. The remarkable women… exemplify the ways *Essence* has defined what it means to be a beautiful Black woman: spirited and spiritual [I invite readers to] [w]itness the rich variety of women whose beauty mirrors the depth of your own" (2005:198).

Appearing not just in print, The Balm has been profiled in dozens of media news clips and documentaries. Seele was even in attendance during the May 1, 2006 CNN special "The End of AIDS: A Global Summit with President Clinton," where Clinton spoke at Mother AME Zion in Harlem. She was featured in Frontline's two-part monumental documentary "The Age of AIDS" and ABC's Primetime special report on the AIDS epidemic among Blacks. All of this publicity, along with the original word of mouth that she counted on in the early days of the movement, helped to increase awareness among not only churches, clergy, and congregants, but also to "outsiders" – those not within the Black Church community.

Conclusion:

Western social movements have three basic traits: they make "[1] claims on target audiences… [2] using various forms of political actions [vigils, rallies]… and [3] commitment" (Tilly 2004:3-4). As this movement's claim maker, Seele made the initial claim on the target audience of the Church, creating AIDS as an issue for the Church in a way that would resonate with its beliefs and morals. The Balm in Gilead developed an understanding of AIDS within the Black Church and, as this chapter shows, created a social movement. Seele contends:

> [it is] not just a social movement among churches, we created… a social consciousness in terms of how you address HIV/AIDS in the African American community, because back then people were talking about faith, but they didn't have a clue. Government wasn't talking about it. People were like, 'what the churches gonna do?' And there were a few of us in the country who really understood that we have to address -- we had to get the churches involved [there were other organizations] but The Balm in Gilead, we were the only ones… We are the only Balm in Gilead today that really have gone further than anybody else in terms of having an international presence and a national presence and everything we do—there is nothing that we don't—everything here is built on mobilizing the faith community to address HIV. And now everybody is talking about faith and HIV… You were not talking about HIV without talking about faith. And now, we were the ones who started that awareness, that conscious awareness, that it had to be done and how to do it.

Theorists Johnston and Klandermans (1995) view "change" as imperative to the "growth or success" of a social movement (13). As The Balm in Gilead's progress has shown, the movement continues to grow. The Balm has branched to include two other programs with foci beyond that of the Black Church and AIDS. The ISIS Initiative is an HPV and cervical cancer program to increase awareness of both illnesses as well as provide comprehensive sexuality education within the context of the Church. The second campaign is the Africa HIV/AIDS Faith Initiative, sponsored in part by the Bill and Melinda Gates Foundation and the CDC. Through this program, The Balm works with churches, mosques, and other religious institutions in Nigeria, Tanzania, Zimbabwe, Kenya, and the Ivory Coast to provide technical assistance and capacity building to the institutions within these countries based on the cultural belief systems of the peoples within these localized religious communities.

As this chapter detailed, Pernessa Seele constructed AIDS as a social problem for the Black Church, creating a moral panic that ignited a social movement. She created The Balm in Gilead to sustain this movement; however, prayer was not enough. In order to receive funding from the CDC the Balm had to extend beyond the "prayer" model to

address actual prevention and education to churches that will, ideally, pass this information on to their congregants. I quoted Seele earlier in this chapter as saying there was no "strategy" involved in creating The Balm, yet I disagree.

As mentioned in the Introduction, The Balm constructed AIDS educational information for the Black Church. I argue that The Balm reframes AIDS information to be church appropriate. As this chapter shows, however, though well intentioned and quite successful, this was a strategic response to sustaining both the movement and The Balm as an organization. For one, The Balm met its goal. Harlem religious leaders acknowledged that AIDS was an issue and religious institutions prayed for those with AIDS. After achieving the goal of prayer, The Balm expanded to education in Harlem and then throughout the rest of the country. The CDC and other government organizations are prevented by law from funding "prayer;" they are allowed, however, to fund religious *educational* programs for community improvement. I am sure Seele's motive for expanding to education was not based on money but on keeping the movement alive, and she needed funds to do so. As explained above, The Balm has expanded beyond even AIDS education in America to address AIDS education and prevention in Africa and other Black American health disparities, such as HPV and cervical cancer – but, this expansion is not just idealistically based, it is a necessity.

Again, I argue that The Balm in Gilead reframes AIDS in a way that resonates with the Black Church. The Balm reconstructs AIDS information to be appropriate for the Black Church. Yet, it is constrained in the ways they can construct AIDS by two key things: 1. the morals and values of a religious institution and 2. the illness itself. I will simply introduce this idea here, but spend the remaining chapters of this dissertation

unpacking this notion. The Black Church is a religious institution with a belief system with different morals and ideas as to what is acceptable. As well-intentioned as they are, Seele and The Balm really cannot change the religious convictions of the Church. As will be described in the Chapter Six, The Balm works within religious ideology to market AIDS to churches, and to be successful The Balm cannot go against this ideology. Similarly, The Balm is constrained by AIDS as an illness. The Balm does not produce AIDS information and facts; it simply represents them in ways that will resonate with the Black Church. There is only so far that Seele and The Balm in Gilead can go while addressing *only* AIDS in the Black Church. The next chapter will address AIDS within the Black Church and the moral road-blocks with which The Balm had to contend to encourage prayer and later education.

Chapter 4:

Sex, Drugs, and the Holy Ghost:

The AIDS Identity within the Context of the Black Church

Introduction:

On December 1, 2005, World AIDS Day, designer Kenneth Cole launched his new public service campaign "We All Have AIDS[30]," with the premise "if one of us has AIDS, we all have it" (K**NO**W HIV/AIDS 2006). This campaign features AIDS activists, political leaders and celebrities, such as Will Smith, Dr. Mathilde Krim, President Nelson Mandela, and even Kami, the five-year-old South African HIV+ Muppet. The slogan, "We All Have AIDS" was featured on billboards as well as

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[30] This campaign was a joint venture with Viacom Inc. and the Kaiser Family Foundation's KNOW HIV/AIDS, public education campaign. Viacom, one of the largest media companies in the world, along with the Henry J. Kaiser Family Foundations and with funding from the Bill and Melinda Gates Foundation, implemented a massive media campaign to promote AIDS awareness within the Black community. Through TV, "radio, outdoor, online, and print media [their mission is] to use the power of media to educate and compel people to act – to protect themselves and get tested for the virus – and to erase the stigma for those infected" (K**NO**W HIV/AIDS, 2006).

The campaign was first launched in January of 2003 and ran public service announcements on billboards, on Viacom's television channels and on the radio. Significantly, they encouraged the writers and producers of TV shows on their networks to have shows addressing HIV/AIDS. This international organization also campaigns in countries of the Caribbean, Russia, and Great Britain. Currently, "Every division of Viacom is involved in the *K**NO**W HIV/AIDS* campaign… [channels] including MTV, BET, VH1, Nickelodeon, CBS, UPN, Nick at Nite, TV Land, Comedy Central, CMT: Country Music Television, Spike TV, and Infinity have all aired PSAs and programs on HIV/AIDS and sexual health, and Showtime, Paramount, the N, and VH1 have produced original programming and movies on the topic" (K**NO**W HIV/AIDS, 2006).

A survey conducted by the Kaiser Family Foundation of a random sample of Blacks showed that among 18-24 year olds who had seen the programming half spoke with their partners about safer sex and "approximately 77% of those who were sexually active said they were more likely to use a condom. Nearly 40% said they had visited a doctor or had been tested for HIV" (K**NO**W HIV/AIDS, 20056).

commercials around the world. This campaign put the stigma associated with AIDS at the forefront, showing how this "STIGMA[31] still challenges efforts to prevent, treat, and ultimately cure HIV/AIDS. The awareness of such STIGMA is a necessary step towards the prevention, containment and eventual eradication of HIV" (We All Have AIDS.com 2006). We All Have AIDS challenged the AIDS stigma buy selling t-shirts that read, "I have AIDS." Although apparently, the AIDS stigma was even too strong for this campaign because soon after these t-shirts went on the market the slogan was changed from, "I have AIDS" to "we all have AIDS." It seems that few wanted to claim that they "have AIDS," even those who would be willing to purchase the shirts to support AIDS charities.

Understanding how people interpret and perceive stigmas associated with AIDS is a major step in developing proper AIDS awareness and successful AIDS education programs. These AIDS stigmas have had a major impact on how people not only perceive HIV/AIDS and those with it but also their susceptibility to HIV infection. This has especially been the case for African Americans, particularly those within the Black Church. This chapter will discuss the importance of understanding the social and cultural constructions of AIDS and its stigmas. I examine the taboo issues associated with AIDS such as drug use, homosexuality and sexuality as described by my respondents and the impact this has on the cultural interpretations of AIDS within the African American community and the Black Church.

[31] Every time the word "stigma" is written in the Mission Statement on the website, it is written in capital letters.

AIDS and Its Stigmatized "Sick-Role":

When we become ill, we take on what Talcott Parsons (1951/1964) referred to as the "sick role[32]." This is the role that society places on those who are ill that allows them to enter into a special relationship with the doctor and/or medical institutions. According to Parsons, there are four basic components to the sick role: 1) the excusal of persons from their responsibilities so they can focus on getting well, or regaining normalcy; 2) the belief that the ailing are not responsible for their illnesses; 3) the individuals' recognition of their illnesses and attempts towards recuperation; and 4.) the willingness of persons to heed the advice of doctors and other health officials in order to restore their health. Of interest to this research is the second component, the lack of an individual's responsibility for her ailment, about which Parsons argues:

> By institutional definitions of the sick role, the sick person is helpless and therefore in need of help. If being sick is to be regarded as "deviant"… it must [be] distinguished from other deviant roles precisely by the fact that the sick person is not regarded as "responsible" for his condition, "he can't help it." He may, of course, have carelessly exposed himself to danger of accident, but then once injured he cannot, for instance, mend a fractured leg by "will power." (1951: 440)

According to Parsons, the person cannot be blamed for her injuries or physical condition while being sick. This individual may have caused her illness, but this person has no control over the state of her illness – over their physical being while sick. She has

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[32] I must note that Parsons focused on the functionality of Western notions of sicknesses. The notion of sick roles, however, varies by location and culture and, as such, is a cultural construction. For example, Kleinman writes that in Chinese culture, the sick individual is "expected to seek treatment, but not necessarily by professionals" (1980: 125). In Chinese society, the occupant of the sick role is not a patient, but a client and, "as a client in the shaman's shrine, he is engaged in rituals and expected to take part in other healing ceremonies, perhaps including exorcism and a spirit marriage" (Kleinman 1980: 125). As a result, based on culture and treatment sought, the sick individual's role expectations vary.

very little control over the impact that her disease/sickness/ailment is having on her body. In this essay, Parsons tended to focus on illnesses such as colds, or, as described in the above quote, "a fractured leg." He was interested in the functional relationship between the doctor and the patient, with the sick role enabling the doctor to occupy the functional role of caregiver. He was interested in the effect that relationship has on society as opposed to simply what it means to be sick. Though Parsons did not believe that people caused their own illness, he acknowledged the impact that illness has on social stability by violating societal norms. Sickness deviates from the normal functioning of society and puts in question the role of the individual within society (Parsons 1951).

Nevertheless, if Parsons examined other more stigmatized medical ills at the time, such as syphilis, he would have seen that blame has often been directed towards the ill for their conditions. In fact, for thousands of years, even after science had an understanding of microorganisms and their impact on health, people were blamed for their illnesses. To illustrate this point, Rose Weitz (1991) points out that though people understood Hansen's Disease, or leprosy, to be caused by a bacterium, it was still seen as "problems of morals rather than medicine" (1991: 39). Weitz contends:

> For much of this century, U.S. leprosaria resembled prisons more than hospitals. Persons sent to these leprosaria could be kept involuntarily for life. They were physically separated from their families, encouraged to change their names to protect their families from disgrace, and sometimes advised to let their families believe they had died rather than expose them to the stigma of having a relative with leprosy. They also were denied the right to vote, to marry, or even to use a telephone. (Weitz 1991: 39-40)

But leprosy – probably the most well known diseases because of its many Biblical references – is but one of the sicknesses that is linked to sin, or some sort of moral shortcoming on the part of the ill. In fact, every book of the Bible makes a direct link

between sickness and sin, with the exception of Job (Weitz 1991). This connection between sickness and sin has a great impact on how illness has been constructed throughout time and how medical institutions have responded to it[33] (Conrad and Schneider 1992). In fact, how we envision the social categories of "evil" and "sickness" have much to do with both the perception and social control of deviance within society (Conrad and Schneider 1992: 17)[34]. Conrad and Schneider (1992) note that collective consensus is necessary in the definition of a "problem" (17).

It is more complicated to understand why the AIDS stigma, in particular, is perceived to be problematic within the Black Church. One cannot simply understand the "social process" through which its associated behaviors, identities, and roles have been defined or constructed as deviant. One must also have an understanding of the Black community and the power bearing institutions within this community that have defined the behavior or identity as deviant, and thus, stigmatized. Understanding how power influences health (Freund 1982: 9) is crucial to understanding the impact of AIDS, not only on individuals, but on the power-bearing institution. In describing how Foucault addresses the display of power within institutions, Turner (1997: xii) suggests:

> Foucault saw power as a relationship which was localized, dispersed, diffused and typically disguised throughout the social system, operating at a micro, local and covert [level] even through sets of specific practices… Power is rather like a color dye diffused through the entire social structure and is embedded in daily practices

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[33] The next chapter will discuss further the emergence of medical institutions as "knowing bodies" responsible for the construction of health information and facts in more detail.

[34] For example, currently, a growing number of school-aged children, mostly boys, are diagnosed as having Attention Deficit Hyperactivity Disorder (ADHD) and prescribed Ritalin when they misbehave. At one point in time these kids were just considered "bad" and disciplined; now they have a sickness (Baughman 2006).

> [as a result] power exists through the disciplinary practices which produce particular individuals, institutions and cultural arrangements.

The ability of a medical professional to define a person or behavior as "sick," and thus place a stigma on that behavior or condition signals the power that medical professionals have over the ill individual. Freund (1982) argues that powerlessness leads to illness[35]. In order to better understand how power-bearing institutions defined AIDS as a deviant illness and the historical context in which that occurred, one must have a better understanding of AIDS and its social constructions.

Constructions of AIDS as Illness and Disease:

I am sure few people – beyond social scientists –think about the differences between illness and disease. Arthur Kleinman argues that when we become ill, we focus on the illness, not on the disease itself. The illness and its impact on our everyday functioning is what forces us to go to the hospital, not the disease. Kleinman (1988) states,

> Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability…

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[35] This argument has important ramifications for understanding the spread of and high incidence rates of HIV/AIDS among more stigmatized groups, such as the poor, women, and IV drug users, and especially rates of HIV/AIDS among those in Sub-Saharan Africa, the hardest hit by this pandemic. Freund (1982) suggests that "our social power… is an important contingency in allowing us to obtain high quality, readily available medical care, and of course, it affects the degree to which we can exercise control over our care" (10). According to well-documented research by social psychologist Hazel Markus, the different ways in which individuals view their future determines their present behaviors. If they perceive many options and control over life and circumstances, they will be more likely to work towards a more positive goal. If they view themselves as having few options, they would be more likely to participate in risk taking behaviors. Markus developed this theory called "possible selves" in a paper published in 1986 with Paula Nurius. "Possible selves" holds great theoretical implications for better understanding various forms of deviant behavior, such as criminal behavior, drug use, dropping out of school, and even sexual risk taking behaviors.

> Disease, however, is what the practitioner creates in the recasting of illness in terms of theories of disorder. Disease is what practitioners have been trained to see through the theoretical lens of their particular form of practice. That is to say, the practitioner reconfigures the patient's and family's illness problems as narrow technical issues, disease problems. [Ultimately,] in the narrow biological terms of the biomedical model, this means that the disease is reconfigured *only* as an alteration in biological structure or functioning. (Kleinman 1988: 3-6)

The sociology of health and illness[36] applies sociological theories and practice to the study of illness and disease and is an essential area of study within sociology because of the social problems illness can create. Kleinman (1988) contends that problems that occur as a result of an illness are the main reasons we seek help. He states, "[f]or example, we may be unable to walk up our stairs to our bedroom… Or there may be impotence that leads to divorce" (Kleinman 1988: 4). In fact, not only is disease and illness constructed, but so too are diagnoses (Brown 1995).

Deborah Lupton (2000) maintains that there are three theoretical perspectives to the sociological study of health and illness. The first perspective is functionalism. As described above in the discussion of Parsons and the "sick role", this perspective maintains that health and illness (and wanting to maintain healthy) require actors to play a role that is critical to the proper functioning of society. In addition, these sick roles allow for an "acceptable" form of deviance, which helps to maintain the social order. The political economy perspective argues that, "good health is defined in political terms not only as a state of physical or emotional well-being but as 'access to and control over the basic material and non-material resources that sustain and promote life at a high level

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[36] I prefer the term "the sociology of health and illness" – as the field is called in Great Britain and Australia, as opposed to the "sociology of medicine" – as it is commonly referred to in the U.S. (Lupton 2000) – because, as Conrad (1997) argues, the sociology of health and illness is a more accurate way of examining the effect of power and social relations on health and perceptions of illness.

of satisfaction,' meaning that a key component of health is struggle'" (Lupton 2000: 8). The third approach, and the approach which provides the theoretical basis of this dissertation, is that of social constructionism.

Social constructionism was heavily influenced by the sociology of knowledge (Berger and Luckmann 1966) and poststructuralist theories of "second-wave feminism and Foucauldian scholarship" (Lupton 2000: 11). Questioning "the existence of essential truths" (Lupton 2000: 11), poststructuralism asserts that "'truth' should be considered the product of power relations, and as such, is never neutral, but always acting in the interests of someone… therefore all knowledges are inevitably the products of social relations, and are subject to change rather than fixed. Knowledge is seen not as a universal, independent reality but as a participant in the construction of reality" (Lupton 2000: 11).

Social constructionist theories were, originally, a subset of the sociology of knowledge[37]. The original theorists associated with the sociology of knowledge school of thought relied heavily on concepts of social norms and argued that all ideas and concepts are *socially constructed*. They ask how interactions require, reproduce, and even alter notions of social facts (as will be addressed in the following chapter). These social norms have an immense impact on the functioning of society, whether it is suicidal behavior or popular style of dress. The norms and facts produced by social institutions and larger societal structures have an enormous influence on the beliefs and functioning of society (Gergen and Gergen 2003). This concept had been around for decades, and originated in the writings of German philosophers and sociologists such as Karl Mannheim who wrote in his 1936 book *Ideology and Utopia* that place, time, and the sets

[37] These theories also include Garfinkel's ethnomethodology as well as the work of Blumer and (arguably) Goffman's symbolic interactionism.

of beliefs of a particular group of people dictated how they view social phenomenon, thus influencing the creation of facts (which will be discussed further in the next chapter). Mannheim (1936/1985) writes:

> a single individual… speaks not a language of his own but rather that of his contemporaries and predecessors who have prepared the path for him, so it is incorrect to explain the totality of an outlook only with reference to its genesis in the mind of the individual. Only in a quite limited sense does the single individual create… the mode of speech and of thought we attribute to him. He speaks the language of his group; he thinks in the manner in which his group thinks. He finds at his disposal only certain words and their meanings. These not only determine to a large extend the avenues of approach to the surrounding world, but they also show… from which angle and in which context of activity objects have hitherto been perceptible and accessible to the group or the individual. (2-3)

This notion of a common and shared understanding of knowledge and reality was further elaborated upon in Peter L. Berger and Thomas Luckmann's 1966 book, *The Social Construction of Reality.* Berger and Luckmann point out that people construct their own reality and this constructed reality is constantly perpetuated by social interactions and the beliefs behind these interactions. As a result, through social interactions, a common social reality is created to define and help understand social phenomena. According to them, society is socially constructed by its members, and these members create its norms, values, and beliefs. Berger and Luckmann believe that we, as individuals, take for granted the social norms within society, failing to realize that they were simply 'invented' at some point in time by a particular group of people with a specific agenda in mind, and are now taken to be true.

Gergen (2003) argues:

> Social constructionist inquiry is principally concerned with explicating the processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live. It attempts to articulate common

> forms of understanding as they now exist, as they have existed in prior historical periods, and as they might exist should creative attention be so directed. (16)

Though heavily influenced by the sociology of knowledge, the application of poststructuralist theories gave new "vigor" to the social constructionist studies (Lupton 2000), especially as it relates to the study of medicine.

The social construction of the concepts of health, illness, and medicine examines how medical knowledge has been created and constructed. However, it is important to note:

> The social constructionist approach does not necessarily call into question the reality of disease or illness states or bodily experiences, it merely emphasizes that these states and experiences are known and interpreted via social activity and therefore should be examined using cultural and social analysis. According to this perspective, medical knowledge is regarded not as an incremental progression a more refined and better knowledge, but as a series of relative constructions which are dependent upon the socio-historical setting in which they occur and are constantly renegotiated. (Lupton 2000: 11)

As a result, this perspective allows for a better understanding of the ways in which medical "truths" have affected the perceptions of health, illness, disease, and medicine, and how they have impacted society and culture (Lupton 2000).

Theories of the social construction of health and illness argue that although illness is very real, the ways in which illness is experienced, and the meanings associated with it vary[38] (Freund and McGuire 1999). To explain this concept, Judith Lorber (1997), like Parsons, uses the example of a broken leg. Though a broken leg is just a fracture of the bone, she argues that the experiences of the broken leg differ. To a business person, a broken leg may be a momentary inconvenience. Conversely, for a professional athlete, a

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[38] The same also applies to medicalized facts about disease which will be discussed in the following chapter; as Charles E. Rosenberg (1989) points out, "every aspect of an individual's social identity is constructed – and thus also is disease" (2).

broken leg can mean a ruined a career. She goes on to explain that the "social effects" of an illness – and in this case she compares pneumonia and gonorrhea – also vary. In terms of the social meaning of an illness, one may be unwilling to disclose one's illness if suffering from gonorrhea as opposed to pneumonia. Different cultural understandings of gonorrhea, as an illness, and the meanings associated with it, may make one infected with it less likely to disclose one's health status. As a result, Lorber points out that the meanings associated with diseases affect the ways in which illnesses are experienced, and as Klein (1988) agues, possibly even treated. Conrad (1997) contends that, "illnesses may reflect deeply rooted cultural values and assumptions" (106). He (1997) goes on to note that, "certain illnesses may engender social meanings that affect our perception and treatment of those who suffer the illness" (108), and this has proven to be the case with AIDS.

As mentioned in the first chapter, understanding the social constructions of AIDS is pertinent to understanding its social impact (Singer 1998; Lindenbaum 1998; Herdt and Lindenbaum 1992; Conrad 1986). Nonetheless, one cannot simply focus on social constructions of AIDS; cultural constructions are also important. As Parsons (1951/1964) points out, social systems and structures are part of larger cultural systems[39]. As such, culture has had a major effect on the ways in which scientific ideas and discoveries are made (Martin 1987). Klein explains: "local cultural orientations (the

[39] In examining the differences between "cultural" and "social" constructions of health and illness – beyond the abovementioned Parsons understanding of social structures as part of cultural systems – I have found that medical sociology literature tends to use the phrase "social construction" in reference to studies on health and illness (see the works of Lorber 1997; Weitz 1991 for examples). Medical anthropology tends to use the phrase "cultural constructions" in reference to the study of health and illness (see the works of Lupton 2000; Herdt and Lindenbaum 1992; Kleinman 1988, 1980 for examples).

patterned ways that we have learned to think about and act in our life worlds and that replicate the social structures of those worlds) organize our conventional common sense about how to understand and treat illness; thus we can say of illness experience that it is always culturally shaped" (Klein 1988: 5). Symptoms of deficient immune systems were originally noticed among intravenous drug users in the mid to late 70s in New York City (Shilts 1987). Though noted as unusual, their symptoms were, for the most part, ignored and deemed a result of drug addiction and an unhealthy lifestyle. However, when otherwise healthy (and often White middle-class) gay men in Los Angles, San Francisco, and New York City began developing illness that were the result of weakened immune systems, scientists took notice, although it was a couple of years before medical officials noticed the similarities between the symptoms experienced by IV drug users and homosexual men (Shilts 1987). It was its initial prevalence among drug users and homosexual men, the modes of transmission, and its fatality that tainted AIDS – giving it a unique stigma. As a result, "AIDS, perhaps more than any other example in the twentieth century, highlights the significance that social meanings has on the social response to illness" (Conrad 1997: 108).

AIDS and Stigma:

In the beginning of *Stigma* (1963/1986), Erving Goffman explains the origins of the word "stigma." The Greeks used this term to, "refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier" (1963/1986: 1). He explains that the Greeks would "cut or burn" these signs into the body to signify their social position as a deviant - a scarlet letter "A," if you will. "Today the term is

widely used in something like the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it" (Goffman 1963/1986: 1-2).

Goffman (1963/1986) describes three types of stigmas: "abominations of the body… blemishes of individual character perceived as weak will, domineering or unnatural passions [and] finally, there are the tribal stigma of race, nation, and religion" (4). Goffman explains that the first type of stigma: "abomination of the body or a physical deformity" (1963: 4), is frequently the result of illnesses. According to Goffman, the medical establishment often creates stigmas by defining certain bodies as "unhealthy." Medical establishments tell "sick" individuals that they are going to take on a new, stigmatized identity – a sick role – that may or may not be temporary or voluntary (Freund and McGuire 1999). As explained above, upon becoming ill, individuals take on the identity or role of patient, someone suffering from an ailment (Parsons 1951/1964). Once someone has a physical ailment or a handicap, Goffman argues, "the medical profession is likely to have the special job of informing the infirm who he is going to have to be" (Goffman 1963/1986: 35). For instance, in her 1980 book, *The Cancer Journals*, Audre Lorde describes how she was defined as a deformed, stigmatized person by medical professionals. Lorde (1980) tells of an incident when a nurse in a rehabilitation facility asked her to wear a prosthetic breast after her mastectomy so as not to upset the other breast cancer patients by showing them her newly deviant and 'deformed' body. Lorde was violating the norms of society by being sick; she was also violating the 'duties' of her sick role by not trying to be 'healthy,' or at least not trying to appear healthy. In addition to her other identities – Black, woman, lesbian, and mother – she took on the additional identity of someone suffering from breast cancer and, later,

became a 'cancer survivor.' As explained above, a similar pattern occurred with AIDS[40] patients who took on not only the identity of a patient, but also the identities of those who were associated with the disease, members of already stigmatized groups.

Goffman's (1963/1986: 4) discussion of the, "abomination of the body or a physical deformity [and] blemishes of individual character perceived as weak will, domineering or unnatural passions" is important to understanding the stigmas associated with AIDS. Those suffering from AIDS in the beginning of the epidemic were primarily gay men and IV drug users – perceived sinners – who were "branded" and disfigured with extreme weight loss and lesions[41] (unfortunate physical markers of their AIDS status) – perpetuating the fear of AIDS and all those associated with the disease.

Louis R. Franzini (1993) compares the different terms used to describe the AIDS stigma including: "pseudo-AIDS… AIDS-induced psychogenic state… AIDS panic… AIDS-phobia… fear of AIDS… delusional AIDS… FRAIDS… excessive concern about AIDS… intractable AIDS [and even] fraudulent AIDS"(72). Franzini goes on to note:

> The fear of [AIDS] is easier to transmit than the disease itself. Evelyn Fisher in 1986 may have been the first to use the term "FRAIDS" to refer to the second

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[40] Though still stigmatized, those who became infected with HIV through blood transfusions were shown more sympathy than those infected through gay sex. There were, indeed, "innocents" in the AIDS epidemic: hemophiliacs and babies born to AIDS infected mothers.

[41] One of the main symptoms of the rare pneumonia, *pneumocistis carinii* (PCP) that many AIDS patients died of during the early years of the epidemic is a quick and dramatic weight loss that occurs shortly before death. In addition, gay men reportedly began dying of another mysterious and rare illness called *Kaposi's sarcoma* (KS) in New York and San Francisco (Patton 1985; Shilts 1985). The symptoms of KS consisted of purplish-reddish lesions throughout the body, internally and on the skin. These telltale marks became 'deformities' or "scarlet letters" identifying the bearer as sick and, often, gay. Although quite different and not as severe, these physical markers associated with AIDS in the early 1980s bore an eerie resemblance to leprosy.

> epidemic – the fear of AIDS. FRAIDS indeed can reach phobic proportions and produce serious negative consequences for individuals whose reactions can become irrational and debilitating… The fear of AIDS has given rise to a variety of suggestions for social restrictions for controlling the spread of AIDS. (Franzini 1993: 71-82)

These restrictions and this fear lead to what Herek and Glunt (1999) refer to as AIDS stigma.

Medical institutions are in large part to blame for the original and continued stigma associated with AIDS. The CDC controlled almost all AIDS information and knowledge, and "was the main source of information during the first year or so for many newspapers: [in many cases] AIDS would not have been mentioned at all, if not for CDC press releases (Schwartz, 1984)" (McAllester 1992: 214). Early reports of "gay cancer," "gay pneumonia," and the "gay plague" eventually became GRIDS or gay-related immune deficiency syndrome[42]. By originally referring to AIDS as GRIDS, the medical establishment told the public not only who AIDS sufferers were going to "*have to be*" when they were sick, but also what they *were*, and *had to be* in order to become infected. When "gay-related" was changed to "acquired," according to Daniel M. Fernando, it appeared as if those who were sick "acquired" the disease – they went out 'looking' for it (Fernando 1993). Stigma was further attributed to AIDS when the human

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[42] Newspaper headlines and news reports from all over the United States and around the world referred to this disease as a gay illness. In "1982 AIDS stories reveal the strong association made between gay lifestyles and the newly discovered condition; from *New York Magazine,* readers found 'The Gay Plague' (Albert, 1986a); from the Philadelphia *Daily News* there was 'Gay Plague Baffling Medial Detectives'; from *The Saturday Evening Post* there appeared 'Being Gay Is a Health Hazard'; and from *The Toronto Star* there was 'Gay Plague Has Arrived in Canada' (the latter three interviewed in Altman, 1986)" (McAllister 1992: 210-211). This occurred despite that cases of heterosexuals suffering from the same immune deficiency had been reported to the CDC since 1981(McAllister 1992). In fact, one of the first people on record as being infected with AIDS was a heterosexual woman (Shilts 1987).

immunodeficiency virus[43] (HIV), the virus believed to cause AIDS, was found to be transmitted through bodily fluids such as semen, vaginal secretions, and blood.

AIDS was fraught with different layers of stigma because, beyond being an illness, it also included social characteristics, which, as described above, became a social identity. Revealing one's HIV status not only revealed one's identity as a patient, but was tantamount to revealing membership within a stigmatized group – for not only was HIV a type of "venereal" disease, spread through stigmatized sexual behaviors, it was fatal; and most important, it originally infected stigmatized groups of people (Alonzo and Reynolds 1995; Fullilove and Fullilove 1998; Herek and Glunt 1988). As a result, AIDS became an identity by which people besides being labeled sick, unhealthy, or dying were also labeled as homosexuals, drug addicts, sex workers, or promiscuous. As Fernando (1993: 10) notes, "[t]here is a long tradition of connecting disease with moral issues: 'Sickness' and 'Sin' are terms which have long been linked together and often interchangeable, especially in times of heightened social anxiety. So there is nothing

[43] The National Cancer Institute's Dr. Robert Gallo and Dr. Luc Montagnier of the Institut Pasteur in France "simultaneously" discovered the virus believed to lead to AIDS. There has been much controversy as to who actually discovered the virus first. According to Randy Shilts' 1985 book *And the Band Played On*, Dr. Gallo of the National Cancer Institute, famous for identifying the HTLV or the human T-cell leukemia virus, the first retrovirus identified in humans, was a noted biomedical researcher. Dr. Montagnier and his team at the Institut Pasteur in Paris had discovered HIV as the cause of AIDS in 1984. Both researchers were working at the same time to find the cause of AIDS, and when Dr. Montagnier's discoveries became known, Gallo believed that there were many similarities between the HIV type 1 and Lai/lllB (originally HTLV-lllB, believed to an isolated sample that the Institut Pasteur received from the National Cancer Institute) discovered by Gallo. Shilts' book was published before both scientists agreed in 1987to resolve the controversy and share credit for discovering HIV. Many believe that Montagnier, indeed, discovered HIV.

intrinsically new in the ways in which AIDS has been culturally interpreted, signified and given strong moral meaning."

The response to HIV was very similar to responses toward other sexually transmitted diseases. According to Brandt (1987), the ways in which society responds to the sick are determined by the ways in which society views those who are associated with the illness. In fact, the ways in which society views those who are sick or associated with an illness is determined not only by how society responds to them in terms of media attention or general public perception, but also in terms of medical resources (Brandt 1987). Illness, as illness, can be stigmatized; it is an "undesirable attribute" (Goffman 1963), but Leary and Schreindorfer (1998) state that people are also excluded or stigmatized if they:

1. pose a threat to others' health or safety (by being dangerous, reckless, or contagious, for example);
2. deviate excessively from group standards (by violating morals, rules, or norms);
3. fail to contribute adequately to the welfare of other individuals or the social groups to which they belong (because they are perceived to be incompetent, irresponsible, infirm, or selfish); or
4. create negative emotional reactions in others by being socially aversive, aesthetically displeasing, or emotionally threatening), (Leary and Schreindorfer 1998: 15.)

Although people stigmatize disease, in general, they do not consider deviant behavior causing all diseases. For example, a physical disability or handicap is stigmatizing, but it is stigmatized because it is an "undesirable attribute" (Goffman 1963/1986), not necessarily because of how the person became disabled. Nonetheless, if a level of blame can be attributed to the person's disability or illness, then it provides justification for the person's misfortune to those who are not infected, psychologically protecting them from the idea of possibly becoming 'infected' with this stigmatizing

attribute (Goffman 1963/1986). For example, the belief that cigarette smokers who develop lung cancer cause their own illness serves psychologically to protect those who do not smoke or are not around cigarette smoke. Similarly with AIDS, religious institutions, but also society in general, identify the disease as well as its modes of transmission as wrong or sinful.

Yet AIDS is different because it is not only a debilitating disease that ends in death, it is also associated with people who are stigmatized, and is transmittable through stigmatized behaviors. Conrad believes that, "the stigmatized meanings of AIDS are still pervasive and continue to shape our responses to the epidemic and affect all those who have the disease" (1997: 108). As a result, Angela Griffin believes, "people are willing to say, oh yeah, I have diabetes, but they are not willing to come out and say that with HIV… They are not going to tell you that they have a family member or a child infected because of so many of the stigmas… it is definitely more secretive, and it's more complicated" (Griffin).

As mentioned earlier, Susan Sontag (1988) contends that all illnesses are metaphors; in fact, Gilbert Herdt writes that:

> AIDS is a double metaphor… It is not only a model *of* the reality of those afflicted by the disease, but it provides a model *for* responding to and representing its risk and contagion for others. Culture shapes our responses to the disease, many of us in the social sciences believe, but, increasingly, the disease is a common denominator of our social life and ontological reality. (Herdt 1992: 5)

The various meanings associated with AIDS have led scholars (Farmer 1992; Hertz 1992; Parker 1992; Treichler 1992; Goldstein 1990) to contend that AIDS has not only been socially constructed, but, more specifically, it has been culturally constructed. One way to combat AIDS is to change "individual attitudes" (Herek and Glunt 1997) by

understanding where cultural constructions of AIDS originate (Lindenbaum 1998) and how these AIDS stigmas are manifested.

AIDS – Them Versus Us:

Around the world, the representations of AIDS vary. Treichler (1992) provides the following examples:

> In a Central African Republic pamphlet on AIDS written in Sango, the immune system is shown surrounding the human figure like a rope; viruses, pictured as beaked and bat like birds, are eating through the protective boundary. In a Brazilian magazine graphic in 1987, HIV attacks cells that look like Caspar the Friendly Ghost, a popular way of illustrating the immune system in 1950s medical textbooks. [U]nderstandings of AIDS (*sida*) among villagers in rural Haiti were diverse until 1987, when accumulated knowledge and firsthand experiences of the disease led to a shared model based on tuberculosis and therefore, believed to be caused by a microbe. [I]n Botswana… with incidence still low, people sometimes talk about AIDS ironically as the 'radio disease' – widely publicized but not yet experienced. (67)

In the African American community, I argue, like most of the country, AIDS has been constructed as a White gay disease. Yet, this social and cultural construction has had different meanings. The remainder of this section will examine how AIDS has been deemed a disease of the "other," and the impact that this has had on the Black community.

In "The Masque of the Red Death," Edgar Allen Poe tells the tale of a masquerade party among the social elite. The host orders the doors of the castle locked to keep the poor and suffering out— those they believe were infected with the plague; they did not realize that the plague was already among them at the party. This story might be considered a metaphor for the behavior of the Black middle class during the initial years of the AIDS epidemic.

According to Bowser (1994), a great failure among social scientists and other researchers is to ignore the class difference among Blacks. "More often, [B]lack social class specific behaviors are erroneously generalized to be common race-specific behaviors… There are very clear social class divisions among urban [B]lacks. These classes are not simply based on differences in income. There are distinct value and class cultural differences." (Bowser 1994: 97). Leslie M. Harris' *In the Shadow of Slavery: African Americans in New York City: 1626-1863,* describes how the Black middle class of New York City would monitor the behavior and dress of the Black working class, and this was especially evident within the Black Churches that were forming during that era by freed, often middle-class Blacks. Cathy Cohen (1999) explains how still today, the Black middle class has the power and the ability within the community to declare a social issue. Middle-class Blacks saw AIDS as a disease affecting the poor, gays, and drug users – the marginal members of the Black community.

The ways in which AIDS and other illnesses are constructed reinforce power relations and structures, in that "medical power not only resides in institutions or elite individuals, but is deployed by everyday individuals by way of socialization to accept certain values and norms of behavior" (Lupton 2000: 12). And for a number of Blacks, particularly the more elite, AIDS was a White gay disease or a disease of drug addicts. Not something good, decent (Anderson 1999) Blacks need to be concerned with. Consequently, like the partygoers in Poe's short story, these Blacks failed to see that 'Death' was masquerading among them until it was too late.

For many within the Black community, HIV was not perceived as being a new issue, "into which enormous group resources must be shifted – which was the approach

in the gay communities – AIDS, though viewed as important, was seen as a phenomenon already understandable through the existing analysis of government neglect, of poverty and of lack of access to health care and education" (Patton 1990: 11). However, there was a community response on more localized levels (Quimby and Friedman 2003; Cohen 1999). There is also evidence that many individuals had participated to help prevent the spread of HIV and have cared for people such as small groups of friends or family members inflicted with AIDS (Hawkeswood 1996).

The damage inflicted on Black communities through the lack of response is documented in Cohen's (1999) depiction of the Reagan years and how damaging they were to the Black community. Blacks were, for the most part, preoccupied with the budget cuts which severely cut funding from programs such as Aid to Families with Dependent Children (AFDC) and Housing and Urban Development (HUD) that many Blacks needed to sustain themselves. Cathy Cohen (1999) argues, "Thus, in the early 1980s, it was the perceived threat posed by Ronald Reagan, not AIDS, which consumed the energy of many Black organizations and leaders" (84). In addition, many jobs were lost as factories moved from urban areas. In times of economic hardships, drug use rises, as it did during this period.

Heroin and crack use was widespread in major U.S. cities, especially New York. With the rise in illegal drug use and trade came a corresponding rise in crime, particularly theft and prostitution. This further distracted Black community leaders from the AIDS crisis. Thus, from the mid-1970s to the mid-1980s, a culture was developing where AIDS could easily spread out of control. Cohen, as well as others (Quimby and Friedman 2003; Weatherford and Weatherford 1999; Fullilove and Fullilove 1999;

Fullilove and Fullilove 1997; Shelp and Sunderland 1992; Dalton 1989), reasons that the lack of a large-scale response to the AIDS epidemic was overt homophobia and class discrimination on the part of the Black community. Many in the Black community also felt that the only Blacks susceptible to HIV were IV drug users, or "junkies" (Quimby and Friedman 2003; Dalton 1989). Cohen (1999) argues that it was these beliefs that prevented an early large-scale community response and allowed AIDS to spread, unchecked, throughout the Black community, the nation as a whole, and the world. For instance, it was not until 1983 that Black newspapers[44] even began to run stories on the growing AIDS epidemic, and when they did, these media outlets ignored the rates within the Black community and mainly focused on scientific findings and the rates among White gay men and occasionally IV drug users (Cohen 1999).

AIDS researchers noted that even when people were part of the initial 'at risk groups,' they wanted to distance themselves as much as possible from their group membership – for it became a disease of the "other" (Abdulrahim 1998; Sharrock 1997). Cath Sharrock (1997) explains, "If the body of the 'innocent victim' can metaphorically displace the 'guilt' for his/her own illness upon the homosexual, the body of the gay man, on the other hand, is forced to bear the mark, indeed the stigmata, of his own transgressive and sinful action" (358).

My respondents noticed similar behavior within their communities. Deborah Levine, The Vice President of Community Development of the National Black

[44] Mainstream media also did not address AIDS in the Black community until the mid-1980s (Cohen 1999). Prior to that, the few times when non-IV drug using Blacks were addressed in AIDS discourse were when Haitians were listed in the CDC's list of the four "at risk groups."

Leadership Commission on AIDS and the former Director for HIV/AIDS Services at Harlem Congregations for Community Improvement, explains, "people were denying their heritage. I'm not Haitian. I'm not this, or that's them. My parents are, or we were born and raised here. I'm second generation. There were just all kinds of things people were doing to disassociate themselves with people who potentially were the most vulnerable" (Levine). People denied their susceptibility to HIV and this helped to reinforce the dichotomies of 'them' and 'us,' in turn helping to fuel the increasing rates of HIV within not only the Black community, but also within the larger society. Since people did not see AIDS as affecting them, they did not see themselves as susceptible and did not protect themselves. AIDS was always attributed to the other, no matter how closely associated one was with the characteristics of those who were initially publicized as being infected. As described above, Deborah Levine knew all too well that people distanced themselves from those associated with the disease. In 1980 Levine, then a student social work student noticed that this occurred when people first began to become sick with HIV.

> I can remember the early days of the epidemic when we started hearing noise about it being the Haitian community [or] White gay man's disease, all that kind of stuff… The sense of isolation that people started to feel and the mechanisms of watching people through that time, figuring out ways to push themselves away from the identified or… "identified" folks who they thought may be carrying this disease or spreading this disease. (Levine)

Kevin McGruder, the former director of Gay Men of African Descent and a current doctoral candidate in History Department at the Graduate Center, CUNY, who lived in Harlem from the beginning of the epidemic, remembers how he and his close friends – predominantly gay Black men – found a way to distance themselves from the disease. "I remember in the 1980s we felt that —at that time I think it was probably still

called GRIDS, maybe—that it was a White disease. I remember people talking about not dealing with White men because, you know, they were carrying [AIDS], and that, I think, was even at the point when people weren't necessarily sure about transmission, but I think it was an understanding [that it was] a sexually transmitted [disease]" (McGruder). Similar to men interviewed in William G. Hawkeswood's ethnographic study *One of the Children,* McGruder points out how White gay men were avoided, even though, as Cathy Cohen (1999) noted, Blacks—including gay Blacks— who after the start of the epidemic had disproportionately higher rates of HIV than any other group.

Interestingly, even those who were infected tried to separate themselves from the identities associated with AIDS. On November 7, 1991, Erving "Magic" Johnson, a basketball player for the Los Angeles Lakers, called a press conference to simultaneously announce his retirement from professional basketball and his HIV serostatus. To avoid rumors of homosexuality, bisexuality, and drug use, Johnson boasted (Biddle et al. 1993) about the thousands of women he had sex with (all the time in a relationship with his current wife, Cookie Johnson); he still maintains that was how he became infected.

But it was not just those of Haitian descent who were "denying their heritage," or Black gay men who were "not dealing with White men;" people were distancing themselves as much as possible from the infected. This especially proved to be the case with the Black Church.

AIDS and The Black Church:

In the early days of the virus, little was known about it except that it was deadly and associated with people on the 'fringes' of society. Such an ambiguous threat

provoked fears and concerns that helped lead to the stigmatization of infected individuals: doctors refused to practice on those infected; HIV positive students, most notably Ryan White, were turned away from schools, and funeral homes refused to bury those infected with HIV. Rev. Claudette Davis noted, "The undertakers at the time didn't want to touch it. In fact, I only know of one undertaker who did all the AIDS related deaths in the BedStuy/Bushwick area, and he was getting like $200 extra to handle these bodies." In the early to mid-1980s, religious institutions were no different. According to Pastor Odelle Davis of Timothy Baptist Church, "Churches represent or reflect; they shouldn't, but they reflect [the] society that they exist in," as do many social institutions.

For well over a century, a number of Black churches have tried hard to improve the living conditions of parishioners and the members of their communities. As I described in the previous chapter, the Black Church holds a prominent role for many within the Black community and Blacks are perhaps among the most "churched" groups in the U.S. (Fullilove and Fullilove 1999). For the most part, however, most Black churches could not get past the stigma associated with AIDS to address the negative effect it was having on the community.

Though many churches thought less about providing guidance and support and more about demonizing those infected with and at risk for HIV[45], there were churches within the Black community – though few and far between – that did acknowledge AIDS within Black communities. Most often, these churches were in urban centers where

[45] In an attempt to stifle the disease, churches and other religious institutions may have believed that by demonizing those infected with HIV, they could, as the old adage goes: "put the scare of the Holy Spirit" in them, thus preventing at risk behaviors and possible infection.

AIDS had taken its biggest toll. While conducting my research I was told of the occasional pastor and/or congregant who pleaded with their church community to accept and pray for people with AIDS. For example, The Balm highlights the achievements of Rev. Dr. Jeremiah A. Wright Jr. of Trinity United Church of Christ in Chicago who, in 1979, started one of the first AIDS ministries. Nevertheless, most churches and other religious institutions could not get past the identities associated with HIV in order to address even the "facts[46]" – such as what AIDS is, how HIV is transmitted, and who is most at risk. As one of the first HIV/AIDS educators in New York City, Seele was amazed by the difficulty in promoting AIDS awareness and admits: "I was very naïve; I really didn't understand stigma, homophobia, or exactly what the lack of response was all about" (Seele, interviewed in Gilbert 2003: 154).

Darlene Cheek, the Coordinator of the Resource Center at The Balm in Gilead and one of the first employees, was amazed that church leaders could not get past their biases to address HIV, in spite of the devastating effect it was having on the Black Church, its congregants, and the community. Cheek says, "And we all knew pastors were burying folk every day from HIV and AIDS! They weren't talking about it. Nobody was saying anything. They were having more funerals than they were having baby dedications. Nobody was saying anything! No one was dealing with it. And no one was giving an outlet to the families because they couldn't say anything. So they had to live in denial because the Church had to live in denial."

My respondents complained that churchgoers and leaders believed that those infected with AIDS had no place within the Church. Deemed sinners, their illnesses were

[46] I will discuss this idea of facts about AIDS more extensively in the next chapter.

seen as a 'punishment' from God (Quimby and Friedman 2003; Weatherford and Weatherford 1999; Dalton 1989). Rev. Alberta Ware, the Director of Church and Community Mobilization of The Balm in Gilead contends that many Black churches still, "are not looking at HIV/AIDS because it has to do with sex, has to do with drugs, has to do with homosexuality." Addressing AIDS would be "blasphemous" (Cheek). As a result, many within the Church have mistakenly believed that by reaching out to people who are suffering from AIDS, they would only be reaching out to homosexuals, prostitutes, and/or drug users. They believed that if they were to address AIDS by developing an AIDS ministry, they would be implicitly condoning behavior that the Church considers immoral.

During my interviews, I inquired as to why church leaders had such difficulty addressing HIV/AIDS, and continuously the same three issues were named: homosexuality, sexuality, and drug use. In fact, The Balm mentions these three issues repeatedly in its publications. Some of my respondents found that by "sticking to the facts," they were able to avoid those issues entirely while still helping those in need. Employees at The Balm maintain that before addressing such facts, the stigmas associated with AIDS – homosexuality, drug use, promiscuity, and the resulting AIDS identity – must first be addressed. Cheryl Sullivan of The Healing Touch HIV/AIDS Ministry at Emmanuel Baptist Church explains that the Church will not address AIDS because it "deal[s] with two of the biggest issues the Church will not historically deal with head on: drug use and homosexuality. And in fact, I'm even gonna be nice. I am putting drug use to maybe a distant three, not just homosexuality, but human sexuality." In order to understand the Black Church's social construction of AIDS, one must

understand the stigmatized behaviors associated with HIV and the implications these hold for the Black community.

Drug Use:

During the 1980s, a number of inner city Black communities were hard-hit by economic depression and a decline in government resources which contributed to widespread drug use and sales. This was especially the case in NYC. Anthropologist Leith Mullings elaborates:

> Marked by the financial and economic crisis of the mid-1970s, the shift intensified an already initiated process of disinvestment. Across America, national government investment in cities, their public transportation and infrastructure, social services and housing declined. National and international corporations pulled up stakes to pursue manufacturing on other continents, eliminating tens of thousands of manufacturing jobs and undermining the unionized sector of the labor force. (Mullings 2003: 177)

Heroin and marijuana use increased in the late 1970s and early part of the 80s, but it was crack cocaine – with its cheap price and almost immediate high – that changed the nature of drug use and abuse in inner city communities (Mullings 2003). As drug sales and poverty increased, so too did crime, adding further despair among many community residents. The response to this "crack epidemic" was the war on drugs, which sent hundreds of thousands of Black men and women to prison. Once released, these people, mostly men, had great difficulty finding "legitimate" jobs, and, often with no other option, they turned again to illegal drug sales, which continued a vicious cycle.

Since so many Blacks felt the impact of drug use during this time, and numerous churches already had ministries to address drugs and alcoholism, addressing HIV in relation to drug use was not as much of a problem as was addressing it in relation to homosexuality or even sexuality. Seele explains: "Drug use! Well, drug use is a little bit

easier… every Black family in some way has been affected by drugs… drug use does not have the same, you know, volatile emotions as [homosexuality]" (Seele). Cheryl Sullivan shares a similar sentiment: "Now you know in the Black Church, you being a drug addict or an alcoholic, [you're] just someone's cousin or uncle. It's very real. It is a part of life, because… the members of the Church are made up of the members of the community. So whatever issues or problems are occurring in the community occurs within the Church."

Latrice Wactor, the Director of the Central Harlem HIV Care Network of the Harlem Director's Group as well as one of two leaders of the Abyssinian Baptist Church AIDS ministry, described a recent incident conducting an HIV education workshop with students from Martin Luther King Jr. High School at the Studio Museum in Harlem. She asked these students if any of them had family members that were HIV positive, and two hands went up. When she asked how many students had family members who had abused substances, "just about everyone's hand went up," in a room of about 75 students. Wactor surmised, "People would rather admit that they know someone or have a family member that is crack addicted as opposed to [someone with] HIV and AIDS" (Wactor). Wactor believes that the fact that only two of these 75 kids felt comfortable disclosing or even knew that their family member may have HIV/AIDS says a lot about the ways in which the disease is viewed in the community[47].

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[47] To provide alternative explanations for Wactor's observations (and to be fair to these kids), the Bureau of HIV/AIDS Epidemiology of the New York State Department of Health claims that among new 2004 HIV/AIDS diagnoses in Manhattan alone, over 40% were among Blacks and over 25% were among Latinos. In Manhattan, Blacks and Latinos tend to reside in Central and East Harlem. The HIV Epidemiology Program of the New York City Department of Health and Mental Hygiene contends that Central Harlem and East Harlem (each with 2.6%) and Chelsea/Clinton (4.3%) have the highest

Richard Ferreira, the Director of Education Outreach for Harlem Congregations for Community Improvement, a Certified Service Partner of The Balm in Gilead, points out why it is "easy" to discuss drug use within the Black Church in relation to HIV.

> The difference is that the community at large knows that there is a high percentage of drug use within their community. So there are many members from the Church who have sobered up and cleaned their lives up, and then they become sort of like the role models of the community because they left the drugs, because they have found the Lord. They're saved, you know. So in that aspect they're more willing to work with substance abusers… There are some congregations which are open to individuals who disclose their [seropostive] status, so they become the ultimate role model: 'I'm HIV+. I'm an ex-drug user. I was incarcerated, but now I'm out; those pillars in the community have become very visual for the Church and the Church is more willing to work with that. (Ferreira)

It should be of no surprise but only a couple of the Balm in Gilead brochures, pamphlets, guidebooks, etc., I analyzed address drug use in relation to the Black Church. For the most part, Balm materials do not address drug use at any great length, possibly because the Black Church is more willing to overlook drug use and have an understanding as to how addictions occur. This is not to say that the Black community and Church are supportive of drug use. In fact, according to Canon Williams, and as discussed by Fernando (1993), Black community and Church leaders, most notably, Congressman Charles B. Rangel, were at the forefront of blocking legislation to allow

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percentages of people living with AIDS in Manhattan as a percentage of the population. Now, I am sure these kids have a number of family members, so I do understand Wactor's summation that more hands should have gone up. However, statistically speaking, it should not be *that* surprising that only two hands went up. In addition, even if, as Wactor contends, more hands should have gone up, these kids simply may not have known if a family member or friend was infected. It may be easier for them to recognize someone who is addicted to crack or alcohol. Their family or friends may be more open disclosing drug addiction within the family, and the kids may be more familiar with the outward symptoms associated with crack addiction than with AIDS. Thus, theoretically, a number of students could have had family members with HIV, but again, they may simply have been unaware of their HIV status.

needle-exchange programs in Harlem. However, as Seele contends, it is easier to address drug use within the Church and community than homosexuality and even sexuality. Agreeing with Seele, Rev. Yoreel Trumpt, from the New York City Department of Health states, "I find it might be a little easier to address alcoholism and drug use because you're not necessarily talking about sex." According to a number of my respondents, much of this resides in the deep-seated homophobia within Black communities.

Homosexuality:

Respondents have noted that a truly effective AIDS ministry must address homosexuality in relation to AIDS and homosexuality in relation to the Black community. AIDS is, as Cheryl Sullivan contends, a "disease that initially had been so closely associated with homosexuality that to this day, if you say that someone is HIV positive, drug use is not the first thing that comes to mind" (Sullivan). Rev. Trumpet maintains, "If you're going to talk about HIV and AIDS, you also, at some point, got to mention homosexuality and what the Word says, and really what the *Word* says. Not what we *think* the Word says. We have to have the conversation. We have to have the conversation about what goes on in our community around homosexuality, and not only here, but globally." Numerous churches believed, and still do, that by addressing HIV they would be condoning homosexuality and same-sex sex. Seele states:

> For many churches, far too many than I would like to say… still associate HIV with homosexuality. They believe that homosexuality causes AIDS. They believe that myth, that fact, that lie. And they hate homosexuals. They just absolutely hate homosexuals, so they connect their hatred of a group of people to this dreaded disease and of course they are mis-educated and misguided... Folks cannot get past their theological position on homosexuality, and if you can't get past that, you can't address HIV because HIV has nothing to do with homosexuality.

Tonya Perry contends that, "Homophobia is a major barrier to this whole thing. You know people can't separate –churches can't separate whatever their feelings are about homosexuality and whatever their ideas are about AIDS, which are erroneous because they don't have the information and so they can't separate them." Because, as Patricia Shelton, an outreach worker at Gay Men's Health Crisis notes, "[churches] preach against a gay lifestyle." Explaining the taboo nature of homosexuality in the Church, Rev. Claudette Davis of Timothy Baptist Church and a volunteer at The Balm in Gilead stated:

> Ohhhhh, don't talk about [homosexuality]. We don't talk about that. That's a closed issue… No one ever talks about homosexuality, that's a no-no. In church there are only two sexes, male and female. And we know, we see them, we know that they are gay and that they are having relationships with men as well as with women or whatever, but you don't mention that in church, no, no. That's a taboo. And even when we become aware of it, it's whispered, but nobody dares bring it out openly. (C. Davis)

Richard Ferreira of Harlem Congregations for Community Improvement agrees. He maintains that in discussing AIDS in the Church, "don't even think about bringing homosexuals in here, because that would mean, sort of like… we were actually accepting homosexual acts, and a lot of our scriptures really kind of attack that. It's not something that's accepted." Rev. Odelle Davis stated during our interview, "the word of God says [homosexuality] is an abomination. Contrary to whatever gay rights they doin'. I know they probably hate my guts, I don't care, but the fact of it is that the word of God [says], homosexuality is an abomination. Clear and simple. No ifs, ands, or buts" (O. Davis). Angela Griffin, the head of the Berean Baptist Church AIDS Ministry in Brooklyn, NY, agrees. "Our church doesn't condone homosexuality as a whole. We've talked about it, but we… definitely don't hate homosexuals, but we don't see it as an alternative lifestyle.

It is not acceptable in the Christian faith" (Griffin). Rev. Michael Jones, assistant pastor of a large Harlem-based Baptist Church states that in terms of homosexuality,

> we hold very firm to the Bible. Now we are not going to beat somebody over the head with it. We are a church… We are welcoming to everybody that comes to the church. However, we are not going to yield on our biblical foundation and what the Bible says. I would say that if you come, if a person comes to our church [who] is gay or lesbian, they will be welcomed into the congregation. [But] there is not going to be same-sex marriage here. There is not going to be affirming of that lifestyle. It is just not going to happen… but we are welcoming of whoever comes here."

Rev. Jones goes on to describe their church's views of homosexuality by providing the following analogy that the pastor of the church gave him: "He said it is like going to grandma's house. Everybody can come to grandma's table, and grandma's not going to kick anybody out. That's her baby. It's her grandchild as much as anybody else. Grandma may not agree with that decision, but they are still welcomed at the table."

Discussions of homosexuality in the Black Church have been going on for decades. Kevin McGruder describes a paper he wrote on Adam Clayton Power Sr., father of Congressman Adam Clayton Powell Jr. and the former pastor of Abyssinian Baptist Church, the same church where Rev. Calvin O. Butts pastors and where Latrice Wactor has her AIDS ministry. McGruder explains that early on, even among well-known pastors, that there was an acknowledgement of homosexuality within the Church; and he describes Powell's 1929 campaign that addresses this issue. McGruder states:

> It was against homosexuality, and not just homosexuality though, homosexuality in Harlem pulpits <laughing>… he called it 'lifting up the standard to the people.' You could see in 1929 he's struggling to kind of understand homosexuality and figure out what the Church should do about it. And he's speaking about it in his sermons that are carried in several Black newspapers. He's criticizing Black Churches that have gay ministers… He was trying to inform himself about homosexuality in 1929, and even with some level of sympathy, because he said that he knows these people just have a moral twist, he's not trying to drive them

> out, but they need to be cleansed and then they can take their place back in the pulpit... It's not like total condemnation.

But regardless of what McGruder contends were the intentions of Powell, he clearly felt that homosexuality was wrong and had no place within a church.

Though Seele believes that the Black Church is homophobic, she stated in a 2005 interview that:

> The African American Church is no more homophobic than any [other faith community]. The fundamental role of the Church is to dismantle that which [the universal church] so successfully created, which is the stigma of AIDS. It is the stigma of AIDS that stops people from getting information, getting treatment, and giving or getting care. We have got to start to dismantle the AIDS stigma, and that's the fundamental purpose of getting faith communities involved. (Seele, interviewed in McKnight 2005: 72)

Seele is not justifying the Black Church's homophobia by saying that the Black Church is not more homophobic as other religious churches and institutions, rather she believes that homophobia among religious institutions helped to influence homophobia within society as a whole and led to AIDS stigmatization. Nevertheless, many of the materials that The Balm in Gilead publishes and produces mention homosexuality in an effort to encourage tolerance. In fact, in 1997, The Balm published *Though I Stand at the Door and Knock: Discussions on The Black Church Struggle with Homosexuality and AIDS*, which featured essays, speeches, and discussions by Mindy Thompson and Robert E. Fullilove, Cornell West, Phil Wilson, and Jeremiah A. Wright, Jr.

Richard Ferreira points out: "Homophobia plays a large part in [a lack of a discussion about AIDS] because we know there are a lot of members in churches who are closeted homosexuals. There is a large amount of individuals in the faith-based

communities who are on the 'down low[48],' so it's sort of like that hidden taboo that's not really talked about." Though it is commonly believed that the Black Church is homophobic, Rev. Osagyefo Sekou of New York Common Ground contends that the homophobia manifests itself differently. During the 2005 Black Masculinities Conference at the City University of New York Graduate Center, Rev. Sekou said, "the Black Church is the most homophobic and the most gay-accepting organization within the Black community." Sekou went on to describe the many instances where gay men and, to a lesser extent, women held very active roles within Black Churches. Fullilove and Fullilove (1997) explain: "Homosexuality is considered among the worst of all sins, but homosexuals are accorded a special status in many churches because they provide creative energy necessary for the transcendent religious experience. Just as women are responsible for nurturing and feeding the congregation, gays in the [C]hurch are responsible for creating the music and other emotional moments that bring worshippers closer to God" (2). Though often times, people within a congregation knew and "accepted" the sexual orientation of their choir directors, lead singers, organ players, deacons, and even pastors, it was never discussed. This made it especially curious when

[48] Common perceptions of the "down low" refer to Black men who are in relationships with women, but who have sex with men. This phenomena has been used as an excuse for the high rates of HIV/AIDS among middle-class Black women. Originally, the term "down low" simply referred to adulterers, but, due in part to J.L. King's best-seller, *On the Down Low: A Journey into the Lives of 'Straight' Black Men who Sleep with Men,* and discussions of the down low on talk shows such as *Oprah*, this phenomena has been associated with Black men and HIV/AIDS. These discussions are highly problematic because they further stereotype Black male sexuality as "deviant" and this serves to shift the focus of HIV education from awareness to blame. Ford, Whetten, Hall, Kaufman, and Thrasher's (2007) article, "Black Sexuality, Social Construction, and Research Targeting 'The Down Low' ('The DL')" is the best research study that I have found that examines this phenomenon, particularly the social ramifications of this label.

many of these prominent young male members within Black Churches began to die mysteriously of 'cancer.'

> At Cornerstone, we had buried at least 12 of our brightest young men, musicians, teachers, extremely educated young men who were also undercover gays. And when they first started dying, people started whispering and talking about it… After these young men started dying and people started opening up to the fact that they knew they were living a gay lifestyle and started buzzing around. We weren't doing anything except talking and then, after the funeral, everything died down again. (C. Davis)

An acknowledgement of being HIV+, was for many, tantamount to an acknowledgment of one's homosexuality (Tewkesbury and McGaughey 1998; Tewkesbury 1994). By denying the disease, the Black Church also silenced the existence of lesbian, gay, and bisexual members within the Church, thereby displaying the power that the Church has to erase an entire group of people – a punishment for their deviant sexuality.

Homophobia within the Black Church and larger Black community has had great implications for AIDS discourse within the Black community and the perceived susceptibility for HIV among Blacks, especially during the early years of the epidemic. Fullilove and Fullilove (1997) found this to be the case in a 1988 focus group with teenage crack dealers who could not dissociate AIDS from homosexuality and believed that only White gay men were susceptible to HIV infection:

> Man: So if you see fo' or five white boys and one nigga, then the nigga got AIDS?
> Leader: No, I meant, no I meant out of every four people that has AIDS, one of them is Black.
> Man: So then you're saying all six are white. That's bullshit! Nigga! [makes a sound like "SMACK"] Man, hell raw, nigga!
> Leader: then tell me the truth – how do you see it?
> Man: It ain't that many niggas f—in'. If they is, then they got a f—ed up

> mind. [Laughter] If they do the white boys influenced them into that shit. But ain't no nigga just gon go f—no… That's the nigga that grew up in the avenues. (Fullilove and Fullilove 1997: 3).

As previously described, in relation to AIDS, McBride (2005), Somerville (2000), and Griffin (2001) all suggest that within Black communities, homosexuality is perceived to be the behavior of the 'other,' mainly Whites, whose sexual perversion spilled out into the Black community. These researchers argue that much of the homophobia in the Black community rests on the fact that many, both Blacks and Whites, do not believe that homosexuality was ever really present in Africa. The various essays in the book, *Boy-Wives and Female Husbands: Studies of African Homosexuality*, describe patterns and instances of homosexuality. Many scholars suggest that homosexuality historically was a Western European and Arab import, something that colonized African nations either adopted or were forced to adopt (Johnson 2001). As late as the early twentieth century, many White scholars believed that Blacks represented "primitive man," a people who, being "closer to nature", did not practice unnatural sexual acts such as homosexuality (Murray and Roscoe 1998). Murray and Roscoe (1998) contend that Whites believed that Blacks practiced purely heterosexual acts, mainly for the purposes of procreation, and homosexuality was something that was invented by more civilized societies.

Conversely, homophobic Blacks – both African-American and African – reverse the argument saying that African homosexuality does not exist because African communities are more civilized in nature, and thus, more moral (Ajen 1998; Murray and Roscoe 1998). For example, in "West African Homoeroticism: West African Men who Have Sex with Men," author Nii Ajen cites Prof. Griff of the rap group Public Enemy as saying, "there's not a word in any African language which describes homosexual…

There are no such words. They didn't exist" (Ajen 1998: 132). Incidentally, "[i]t is estimated that there are between 2,000 and 3,000 languages spoken on the African continent, with possibly as many as 8,000 dialects" (Africanlanguages.com 2005), suggesting it is difficult to nearly impossible to know whether or not the word "homosexual" exists in any of these languages. Regardless of the existence of an actual word, same-sex behaviors and relationships certainly existed (Murray and Roscoe 1998). Male transvestites were referred to as *mashoga* in Mombasa, *makhanith* or *mahanisi* in Zanzibar (Amory 1998: 68); both male and female gays as *mke-si-mume* (Haberlandt 1998: 65); and *khanith* for the "third gender category" (Amory 1998: 74). Each of these societies understood these behaviors differently and ascribed different meanings and values to them. To some this behavior was acceptable, to others, deviant. Yet, it is modern Western culture that ascribed gay identities to those associate with homosexual behavior (Greenberg 1990).

David F. Greenberg's *The Construction of Homosexuality* (1990) argues that homosexuality is a social construction that originated in the association of sin and sex. He writes that homosexual sex[49] was frowned upon for the same reasons masturbation was frowned upon; it was believed that it was a, "wasteful loss of semen… no different from throwing away money" (Greenberg 1990: 362). Greenberg explains that even for heterosexuals, "intercourse between spouses should not take place too frequently" (1990:362), and when it did, only for the expressed purposes of procreation. Using any sort of birth control or having non-vaginal intercourse was a sin. Believing that men only

[49] Most work did not tend to focus on homosexual sex between women. Often, physicians, and other scientists did not believe that women had an actual "sexuality" or received any gratification from sex. They mainly engaged in sexual behavior to please men or to procreate (Green 1998).

had a limited amount of semen, it was a sin to "spill" semen, tantamount to abortion (Greenberg 1990). By controlling sex and procreation, religious institutions were able to control society. Foucault believed that (1978/1990) power is maintained through the oppression of one group by another, and sexual oppression is an example of this. Similarly, any notion of deviant sexuality, according to Foucault, had to be "driven out, denied, and reduced to silence" (4). It was during the late 1800s that homosexuality went from being a sin, to a crime. It was in 1869 that a Hungarian physician, K.M. Benkert, coined the term "homosexual" in response to what became known as "Paragraph 175," a section of German legal codes banning same-sex sex (Conrad and Schneider 1992). Benker, writing under the assumed name of Kertbeny, describes homosexuality in this way:

> In addition to the normal sexual urge in man and woman, Nature in her sovereign mood had endowed at birth certain male and female individuals with the homosexual urge, thus placing them in a sexual bondage which renders them physically and psychically incapable – even with the best intention – of normal erection. This urge creates in advance a direct horror of the opposite [sex] and the victim of this passion finds it impossible to suppress the feeling which individuals of his own sex exercises upon him. (Conrad and Schneider 1992: 183)

Homosexuality went from being a criminal behavior to a sickness to, eventually, a lifestyle or an identity (Conrad and Schneider 1992). Somerville argues that (2000) there is the belief that this behavior occurred mainly in Western nations, leading to the idea that homosexuality is something in which only Whites participate. Already oppressed, Black lesbians and gays were often unable to claim a gay identity[50], supporting the association of homosexuality with Whiteness.

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[50] There are numerous notable exceptions to this. Many important Harlem Renaissance figures such as Bruce Nugent, Langston Hughes, Zora Neale Hurston, Alaine Locke, and Angelina Weld Grimke all participated in its "lesbian and gay subculture" (Battle and

Nevertheless, more researchers and scholars are addressing homosexuality in Black communities and within institutions such as the Church (Constantine-Simms 2001; Dyson 2001; Griffin 2001; Johnson 2001) and the family (Battle, Cohen, Harris, and Richie 2003; Bennett and Battle 2001; Hawkeswood 1997). Most of this research began in the early 1990s, due, in part, to the AIDS epidemic. Homosexuality in the Black community could no longer be denied when so many young Black men were dying of AIDS. As I mentioned in Chapter One, homophobia in the Black Church and the larger Black community prevented frank discussions of HIV and AIDS, and resulted in a denial of homosexuality in the Black community. AIDS made it clear that there were Black gays and lesbians and acknowledging them and homophobia in the Black community became a matter of life or death.

Riggs (2001) argues that homosexuality in the Black community is so frowned upon because gay men are perceived to be willingly giving up their male privilege – their masculinity – and often in the Black community this is the only privilege that Black men have. Bell hooks argues that lesbianism provokes a similar confusion regarding Black women. Black lesbians are perceived as giving up their femininity, not procreating, nor letting the Black man have his due (hooks 2001). Barbara Smith states:

> One of the reasons that I have thought for homophobic attitudes among women is the whole sexual stereotyping used against all Black people anyway, but especially women in relation to homosexuality – you know, the "Black bulldagger" image. Lesbianism is definitely about something sexual, a so-called deviant sexuality. So the way most Black women deal with it is to be just as rigid and closed about it as possible. White people don't have a sexual image that another oppressor community has put on them. (Smith and Smith 1983: 124)

Bennett 2005: 415). There are also notable gay and lesbian singers, musicians, scholars, and activists such as Bessie Smith, Alice Walker, Audre Lorde, Luther Vandross, and Baynard Ruskin.

Ultimately, Kevin McGruder contends: "there's a feeling that by affirming homosexuality… they are suggesting that it leads to the deterioration of the Black family." Due to slavery (Gutman 1976), the Great Migration (Lemann 1992), and the perceived instability of the Black family, as well as the influence of the Church and religious ideology and doctrine, the family has become the most prized and valued institution in the Black community. According to McGruder, anything that challenged the stability of the family – such as a lack of adherence to traditional gender norms, homosexuality, or promiscuity – was frowned upon within the Black community.

Douglas (2003) argues that Blacks have been trying to distance themselves from deviant forms of sexual expression for over 100 years, leading to the denial of homosexuality in the Black community and extremely homophobic beliefs on the part of the Church. Scholars (Douglas 2003: Newman 2002) argue that it is not homosexuality that is at the root of homophobia within the Black community and Church, but it is sexuality, or better yet deviant sexuality, and the oppression that Blacks faced based on their sexuality. Examining homosexuality and homophobia in the Black community is a separate dissertation unto itself. There are a whole slew of different issues that can be examined in relation to AIDS discourse. Collins (2004), Douglas (2003) and Newman (2002) all contend that until Blacks, and especially the Black Church, come to terms with Black sexuality, AIDS will continue within the Black community.

Sexuality:

Black churches vary on their discussions of sex and sexuality; yet, according to my respondents, these discussions only occur in certain contexts. Rev. Evatt Mugarura, the Director for the Africa HIV/AIDS Faith Initiative at The Balm in Gilead, contends:

> The bad thing is that we think the Church or Muslim community [don't] talk about issues of sexuality, but they do. We are the people who wed couples, you know, in the churches. Before they are wedded, they're instructed, ok? And the instruction is mainly on sexuality, how do you relate sexually… how do you insure that this sex is done properly… this is done within churches' walls, ok?

Rev. Mugarura points out that women's groups and youth groups within the Church have all addressed sexuality in some form. He further notes, "So the Church has never shied away from addressing issues of sexuality, but the world thinks that the Church looks at sexuality issues as a taboo. To talk about them is like a taboo, which I deny here, as a Christian in the Church, who has been in the Church for all these years. It's not like that" (Mugarura). Cheryl Sullivan agrees. Her church, Emmanuel Baptist Church, has offered classes on human sexuality called "Sex in the City" for the past two years, and in fact, we met up for our interview immediately after the last class ended. This course, taught by the church's pastor, Rev. Trufant, explored human sexuality, dating, sex before marriage, homosexuality, and their corresponding biblical interpretations. At Emmanuel, sexuality has even been discussed openly within the church through sermons and within a variety of ministries, and according to Sullivan, "people seemed to receive it very well… I didn't see anyone get up and leave."

But not all churches are this open. Rev. Claudette Davis, of Timothy Baptist Church, left her church of 60 years, Cornerstone Baptist Church, because of the conservatism around sex and sexuality, which hindered the development of an effective AIDS ministry. She points out an instance where she had placed condoms, along with other AIDS relevant information, in the church, and described a conversation she had with a deaconess at Cornerstone about the condoms:

> People just picked them up, looked at them, and quietly put them in their pocket or pocketbook and never said anything. But there was one deaconess, and she picked up one and dropped it like it was burning hot and I said:
>
> "What's the matter?"
>
> "Oh, that's not supposed to be in the church" [she replied].
>
> Oh, that's not supposed to be in the church? I said, "What is it?"
>
> She would never identify what it was. She just kept standing there telling me, "that's not supposed to be in the church."
>
> [She said,] "Who told you [that] you could bring those to church?"
>
> I said, "I didn't ask anybody. I was asked to bring them to this health session and I put them on the table… there is no sign on them that says what they are or what they are for, but they have been disappearing, so [I] didn't say anything … you are the first person who asked me what were they doing and I asked you why and you couldn't come up with why, you just wanted to tell me that they had no business in the church. That's your opinion. I can't argue what with you."
>
> She was adamant that this was not supposed to be in the church… I didn't move those last few ones, but they went away before the day was over, they were gone. (C. Davis)

When I asked Rev. Davis if the deaconess explained why the condoms should not be allowed in the church, Rev. Davis said, "No, she wouldn't touch on it. But I know she went back to the pastor who didn't have enough gumption to speak to me either, but after that, I noticed it got really chilly when I started asking about AIDS programs. I was told that 'we are not focusing on that right now… We will discuss it later.' It was getting very frustrating at Cornerstone. Very frustrating."

Darlene Cheek believes that it is sex, not necessarily the sexual orientation of who is infected, that is difficult to address. She states, "It's sex in the Church, and that's one thing the Church doesn't like to talk about. Doesn't like to deal with. Most churches, we

don't want to talk about it, don't want to teach it. And yet, you have one of your higher rates of birth by youth and adolescents in the Church having babies" (Cheek).

But again, I agree with Rev. Mugarura; the Church does address sex and sexuality, but I have found that this most often occurs by either preaching abstinence or sex for the purposes of procreation in marriage, or preaching against premarital and homosexual sex. According to Cheryl Sullivan:

> [Churches] will tell you what you are and what you aren't supposed to do, they will tell you some of the consequences of your behavior, but they will not give you a true to life, biblically based, explanation or exploration of the issues… You can address it from the pulpit: 'Y'all going to hell if you are fornicating.' Ok, fantastic, let's have this dialogue… Or they will say, 'if you are gay, you are doubly damned.' Fantastic, let's have this conversation… And the great thing about having a class like Sex in the City is there is this dialogue, there is the communication, as opposed to it simply coming from the pulpit… If I am sitting there, thinking, that don't sound right… You can't raise your hand in the middle of the sermon, people will think you are just witnessing.

With teenage pregnancy, out of wedlock births, sexually transmitted diseases and infections (STDs/STIs), along with conservative stances toward discussions of sexuality in schools, it is not just the Black Church, but society as a whole, that has difficulty addressing issues of sexuality, especially to our youth. Cheryl Sullivan contends, "The Church doesn't want to sit around and talk about human sexuality when it seems that people are not comfortable talking to their families about it." Darlene Cheek explains: "I taught a class, a youth class, one day and I'm like, [the babies the kids are having] didn't come in through the air… Think! She pregnant! She didn't drink a glass of water. Just think about it!"

There are some churches that openly address issues of sex and sexuality. The AIDS ministry of Jennifer Smith's Bronx based AME church hosts a number of youth events. Smith described one event where they, "[give] out condoms and stressed safe

sex." But she maintains, "for our young people, basically, our stand is that of abstinence, and we are not, no way, no how, encouraging them to be sexually active."

Douglas (2003) contends that ideas of the Black body and Black sexuality helped fuel the conservative stance of the Black Church and community towards sexuality and other forms of "depravity." This conservativism has its basis in slavery and the history of Blacks in the Americas. Cornel West suggests, "There is no way of educating Black folk without teaching history and there's no way of understanding why in fact we are unable to come to terms not just with homophobia, but all forms of human sexuality" (1997: 13).

Though the Black Church is not unique in its opposition to discussing sex and sexuality, the reasons for such opposition are unique. This originated with the dehumanization of Blacks during slavery, when much of the focus was placed on Black sexuality and the Black body (Douglas 2003; West 2001). Blacks were portrayed as sex-crazed 'bucks' or 'jezebels' with no sense, morals or decency (West 2001). The notion that Blacks were little more than beasts worthy of ownership made it much easier for Whites to justify slavery (Douglas 2003). By degrading Black sexuality and the Black body, Whites further strengthened the power they had to exert control over Blacks (Collins 2004; Douglas 2003). To distance itself as much as possible from this negative portrayal of Black sexuality, the Black Church (like most other religious institutions), and the Black community as a whole, took a very conservative stance towards sex and sexuality and all things relating to deviant sexuality, such as pre-marital sex, extramarital affairs, births out of wedlock, and especially homosexuality (Douglas 2003).

Kelly Brown Douglas (2003) provides an extremely comprehensive discussion of the Black Church and sex in her book: *Sexuality and the Black Church.* This largely

theoretical piece explores issues of sexuality and womanist[51] theology. Douglas concludes that faith, religion, and spirituality have influenced the lives of Black Americans, and in particular, the role they take within their communities. West (1997: 13) points out, "as Professor Douglas says with such insight and perspicacity, history tells us why it is that Black folk have been unable to candidly, critically, frankly talk about sexuality." Douglas notes that although the Black Church, as an institution, is homophobic, this homophobia is rooted in the Black sexual oppression experienced at the hands of Whites. She details how Whites treated Blacks and the Black body, and how the dual fascination and repulsion of the Black body influenced the perceived acceptability of enslaving it. This perception of Black sexuality has affected the ways Blacks are seen by both Whites and by themselves. Douglas argues that the Black Church, born out of the oppression that Blacks experienced before and after liberation, was directly influenced by these White perceptions. She further applies Foucault's theories of sex and sexual oppression to the experiences of Blacks, whereby he argues that all forms of sexual oppression are based in power struggles. By oppressing the body and sexuality of another individual, control is enacted over them. But Douglas (2003) argues that Blacks, especially the Black Church, took an extremely conservative stance towards sexuality and sexual depravity, as a way of both freeing themselves from their White oppressors and proving themselves –their sexuality and body—as legitimate. In a vein similar to Douglas' work, Patricia Hill Collins (2004) and Cornel West (1997) discussed the links between sexual and gender discrimination, homophobia, class discrimination, and how

[51] Womanism, a term coined by Alice Walker, is a form of Black Feminism in which the intersections of race, gender, and class are addressed. According to Walker it "is to lavender as feminism is to purple."

they are all connected by describing the Black and especially middle-class attempt to regain control of Black sexuality and the Black body with an emphasis on decency and respectability. As Kenyon Farrow of the New York State Black Gay Network points out the "Black Church [and] Black middle-class have [always] chased respectability and morality."

Black Churches Confronts AIDS:

It has become clear for Black churches and the larger Black community that AIDS is no longer a gay disease. Through my interviews I discovered, many churches have recognized the need for AIDS education, but do not know how to respond. Seele states, "I think most people – most churches – did not respond in the early days because they did not know what it was, they did not know what HIV was. The national public media, public health put it out there that it was a gay disease, a gay White disease, a gay Black or White disease, and the Church, historically, has not been homosexual affirming so that was a turnoff right there."

On the other hand, what were clear were the modes of transmission. Even though many of my respondents did not condone homosexual behavior, or any of the other behaviors associated with HIV transmission, they still had AIDS ministries within their churches. The staff at The Balm in Gilead acknowledges the importance of recognizing the links between homosexuality, sex, and IV drug use in AIDS education, and as a result, the materials they produce and their campaigns work, "to remove myths and unfounded fears by educating people about what AIDS is and is not and about the full impact of HIV/AIDS on the community" (The Balm in Gilead 2003b: 2).

But Rev. Claudette Davis uses a different tactic to discuss sexuality within the Church. She states:

> Sex is a gift from God. The first time I mentioned that someone looked at me and said "what?" Think about it. Adam was in the garden alone. He was naked. He named all the animals. All the animals had mates. He was alone. God saw he was alone and created a mate for him. And let's look at the issues of how he created them. Adam had the instrument to give. Eve was conceived with the part that was to receive. So the giving and the receiving was already decided, who was the giver and who was going to be the receiver… it was never identified in the Bible as a gift, the gift of the spirit… [but] when you tell them that in church they look at you and say, 'oh my God, did you hear that?' (C. Davis)

The immediate association of AIDS with homosexuality, promiscuity, and IV drug use prevented religious leaders from addressing AIDS. Regardless, Black churches were discovering that the overwhelming effect of AIDS on the Black community was forcing them to look beyond homosexuality, sex, and drug use in order to confront the disease. Wactor notes:

> I think… the mode of transmission and how it 'came down the pipe' initially, is why the Church [ignored HIV]. You either had to be promiscuous or you had to be a drug user… or a homosexual, and those are three categories that The Church frowns upon. But those three categories probably define so many in [the] Church [and a] large population of The Church fall into those three categories sometimes, some way, somehow. (Wactor)

A number of churches have avoided issues of sex and sexuality for decades. "We are burying our heads in the sand, not wanting to deal with it" (Cheek). By not dealing with homosexuality, sex, drug use and abuse within the Black community, these churches are also not dealing with the ways in which HIV is transmitted, or on the "[tremendous impact this has] on us. So our children are dying and we can talk about the men that are being released from prison and they're coming back to their partners, to their women, and coming back to the churches. We're not dealing with those issues around getting tested and what are the risks, and those kinds of things, and I think that we have to be more real

about that" (Perry). For the impact of AIDS is far too great and is forcing these Black churches to come to terms with drug use, homosexuality, and sexuality. The ways in which many religious leaders tend to deal with social problems is through preaching and the development of ministries. The Balm in Gilead has helped over 10,000 churches confront the AIDS epidemic and has helped in the development of hundreds of ministries around the world. The main obstacle of these ministries are the same that The Balm face, overcoming the stigmatized ascribed AIDS "identity," and the best ways to overcome this identity is to educate congregants and community members about the "facts."

AIDS Identity:

Even though in the beginning of the epidemic everyone from gay men and intravenous (IV) drug users, to housewives, children, and doctors was diagnosed with AIDS, medical establishments and the media framed AIDS as a White gay disease, or a disease that only affects IV drug users, gay men, and sex workers (Shilts 1987). As a result, AIDS became a symbol, or a metaphor, of the types of people who were infected (Patton 1990; Sontag 1989; Weitz 1991). As discussed above, although AIDS is an illness, it is also a social construction with meanings and beliefs associated with it (Freund and McGuire 1999; Weitz 1991), and therefore, there is much variety in how AIDS is constructed.

The extremely negative societal response to HIV/AIDS led to the formation of stigmatized identities among those infected[52] (Baumgartner 2001; Lewis 1999;

[52] It is important to note upfront that I am not theorizing or referring to how those living with AIDS internalize or may even combat this AIDS identity. I am only interested in the fact that other scholars have made reference to the existence of an internalized AIDS

Tewksbury and McGaughey 1998; Tewksbury 1994). These academics all argue that the stigmas associated with AIDS – often those of fear and discrimination – are a commonality shared by those living with AIDS; and these shared experiences, along with the common meanings of HIV transmission and infection become an" incorporated" (Baumgartner 2001) part of their identity. Manuel Castells (1997) argues, "[i]dentities are sources of meaning for the actors themselves, and by themselves, constructed through the process of individuation… Identities can also be originated from dominant institutions, they become identities only when and if social actors internalize them, and construct their meaning around this internalization" (7). Simply put, identities are socially constructed. But Castells (1997) writes:

> The real issue is how, from what, by whom, and for what. The construction of identities uses building materials from history, from geography, from biology, from productive and reproductive institutions, from collective memory and from personal fantasies, from power apparatuses and religious revelations. But individuals, social groups, and societies process all these materials, and rearrange their meaning, according to social determinations and cultural projects that are rooted in their social structure, and in their space/time framework… Who constructs collective identity, and for what, largely determines the symbolic content of this identity, and its meaning for those identifying with it or placing themselves outside it. (7)

The influence that power-bearing institutions have over the creation and the formation of one's identity has special relevancy for the creation of an identity associated with illness, particularly one as contested as AIDS.

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identity that results from the stigmas associated with AIDS. Though fascinating, the experiences of those living with AIDS is not particularity relevant to the arguments I am making in this dissertation. I examine how *others* view those with AIDS, not how those with AIDS internalize these views or how these views influence aspects of their identity making. In this dissertation I focus on how ideas about AIDS influence societal perceptions, *not* how ideas about AIDS influence individual self-perceptions.

As with all major illnesses, the meanings that the experience of living with disease has on individuals both affect their sense of identity and the ways in which they self-identify (Barker 2002; Pike 2002; Gordon 2000; Axtell 1999; Linton 1998; Cerulo 1997; Conrad 1987). The experience of living with such a socially stigmatized disease as AIDS (Herek 1999; Alonzo and Reynolds 1995) has led to the development of a unique social and health-related identity[53] on the part of those infected. In 1994, Richard Tewkesbury conducted a study of HIV+ people and discovered that the labels others place on them had a negative impact on their understanding of their own identities. Lewis' 1999 findings were similar to those of Tewkesbury who found that the processes of "accommodating" to living with HIV and the "stigmatized identity" associated with it helped to create a separate identity. Whether based on fact or fiction, these labels were so powerful that they developed identities unto themselves. Consequently, AIDS is not only an identity that is created based on an individual's own seropositve status, it is also an identity created by society, made up of societal understandings and beliefs of the labels and meanings associated with the transmission and state of HIV infection. Thus, this identity becomes an ascribed identity placed on those actually infected, and those believed to be infected, with HIV.

Ascribed identities are a set of assumptions based on stereotyped beliefs and, often, fears associated with an individual believed to be from a particular group or social category (Kramer 2001). Ascribed identities are, "characteristics that carry with them a

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[53] Like movements such as the gender based women's, sexuality based lesbian and gay, class based labor, and race based civil rights movement, AIDS is similar to the health and ability-based 'disability identity' in that it is an identity based on the functioning of the body (Linton 1998), but the AIDS identity differs in that the intersections of race, class, gender, and sexuality play a major role in this identity formation, possibly even more so than the health status of the individual.

set of assumptions about culture, status, and behavior that are highly salient for majority category members" (Kanter 1977a, interviewed in Kramer 2001: 176) or what people believe to be "salient" for these "category members." In this dissertation, I am not so much interested in the individual, personal experiences of people's understandings of their own HIV or AIDS identities. Rather, my focus is on the ascribed identity made up of the stigmas perceived to be associated with HIV/AIDS, such as promiscuity, homosexuality, drug use, illness, and death and how these ascribed AIDS identities vary by community, and, in the case of the Black Church, how an institution can impose ascribed AIDS identities.

As shown above, for many church members, like AIDS the illness, the AIDS identity holds different meanings for different individuals and groups. Homosexuality, drug use, promiscuity – albeit all negative in the larger, mainstream community – hold slightly different meanings for my respondents. I conclude that AIDS has been constructed differently within the Black community and, as a result, understandings of AIDS and the AIDS identity vary, based on community. Different understandings of and experiences with promiscuity, homosexuality, and drug use have informed the ways in which AIDS has been perceived. As I showed above, AIDS holds distinct social implications for the Black community and especially the Black Church (Quimby and Friedman 2003; Cohen 1999). One of the major challenges that The Balm in Gilead faces is encouraging the Black Church to view the illness of AIDS unobscured by the stigmas associated with the disease. Once this is done, the Church can more easily see the task facing them – to facilitate the development of AIDS ministries and outreach

programs and bring awareness of AIDS to congregations and communities, reminding these churches of their commitment to care for the suffering.

The AIDS identity is a theoretical construct. Exploring how this identity was formed within the larger society, and more specifically within the Black Church, the AIDS identity tells us more about the person perceiving the identity then the inflicted person herself. The "We All Have AIDS" campaign is significant because it recognizes the identities associated with AIDS and the need that people have to distance themselves as much as possible from this 'identity.' "We All Have AIDS" is a direct response to the stigmatized identity associated with AIDS – something that Pernessa Seele and The Balm in Gilead have been trying to help churches overcome for over 17 years. The Balm recognizes that the AIDS identity means something different to the Black Church, and restructures AIDS to address their particular perception of the AIDS identity. The first step for The Balm is to help churches recognize all aspects of HIV/AIDS, such as the people "associated" with AIDS, the devastating nature of the disease, and ways in which HIV is transmitted.

Conclusion:

The complexity of addressing AIDS within the Black Church stems from the difficultly a number of churches had in looking beyond their "AIDS identity" to view AIDS as an illness, and the person infected as someone with a "sick role." Parsons states: "there may be some question of whether 'being sick' constitutes a social role at all – isn't it simply a state of fact, a 'condition'?" (1951/1964: 436). As Parsons noted, there is a role associated with being ill and there are certain behaviors expected from both the

person who is ill and from society. Just as Freund (1982: 132) argued that, "social control pressures 'produce' physical disease, illness and death," and following that, "sick roles" (Parsons 1951), I also believe that social control pressures produce identities, which are combinations of societal, or even community-specific conceptualizations of the illness as well as the behaviors associated with it. Similarly, I would argue that sometimes one's illness has a role, but that AIDS is unique in that the person living with AIDS has a different type of sick role – an identity. She is not only playing the role of the "sick" person, but, as discussed above, she has been given the "role" of someone who contributed to her own illness – this individual responsibility has a special meaning for the Black Church. As this chapter has shown, an ascribed AIDS identity was formed**,** and ascribed Aids identity exists and this AIDS identity holds particular implications for the Black Church, the "controlling institution" within the Black community. Thus, as a result of the initial reporting on the nature of the illness, the modes of transmission, and especially the behaviors of those originally associated with AIDS, the disease took on an identity of its own, within all facets of society but especially within religious institutions.

There is a voyeuristic aspect to becoming aware of someone's AIDS serostatus. With AIDS, religious leaders often believed it was possible not only to know how infected individuals lived their lives but also how these individuals would die. Therefore, many felt, especially those within religious institutions, that AIDS was the physical manifestation of their sins (Sharrock 1997) and this had great implications for the Black Church's perception of AIDS.

As previously mentioned in this chapter, AIDS became a disease of "the other" (Sharrock 1997). Patricia Hill Collins (2000) talks about the other in terms of "binaries"

in relation to Black women and oppression. Collins (2000) states: "One part is not simply different from its counterpart; it is inherently opposed to its 'other'" (70). In terms of "binary thinking" (Collins 2000: 70), AIDS was the opposite of desired possibilities. As a result of all of the '–isms' associated with AIDS, the AIDS identity became the most stigmatized side of many unfortunate dichotomies: it was gay instead of straight, Black or person of color, poor, unhealthy, and for the Black Church, sinner – it became the complete opposite of the "mythical norm[54]." As Pernessa Seele maintained in a 2005 interview: "We have to continue to work hard to get those churches that are so wrapped up in the stigma of AIDS that they have not been able to break through to address the problem of AIDS" (Seele, interviewed in McKnight 2005: 74). For although there have been countless Black churches that have developed AIDS ministries since the start of the epidemic, such as Rev. Dr. White's 1979 AIDS ministry, most Black churches have avoided addressing AIDS because of the identities associated with it and their concerns that they would be condoning stigmatized behaviors, and would become known

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[54] We are all held up to a particular "norm" within society, a norm that does not exist. Audre Lorde calls this the mythical norm. Lorde coined this phrase in "Age, Race, Class, and Sex: Women Redefining Difference," an essay that appeared in her 1984/1992 book *Sister Outsider: Essays and Speeches by Audre Lorde.* Lorde writes:

> Somewhere, on the edge of consciousness, there is what I call a *mythical norm*, which each one of us within our hearts knows 'that is not me.' In America, this norm is usually defined as white, thin, male, young, heterosexual, Christian, and financially secure. It is with this mythical norm that the trappings of power reside within this society. Those of us who stand outside that power often identify one way in which we are different, and we assume that to be the primary cause of all oppression, forgetting other distortions around difference, some of which we ourselves may be practicing. (Lorde 1992: 116)

This is similar to Goffman's argument that everyone is stigmatized in some way, shape, or form. "There is only one complete unblushing male in America: a young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record of sports… Any male who fails to qualify in any of these ways is likely to view himself – during moments at least – as unworthy, incomplete, and inferior" (1963/1986: 128).

as 'the AIDS Church', or "'the gay Church,' 'the crack Church,' and 'the condom Church'" (The Balm in Gilead 2003a: 19). This is similar to Sullivan's contention that Emmanuel, with its "progressive" pastor, active AIDS ministry, and gay population, is known as "the gay church" (Sullivan).

As this chapter examined, understanding a community's perspective of and relationship with the AIDS identity helps organizations and institutions to better respond to how AIDS is viewed by that particular community. The views of the Black Church are similar to, "other cultural products, in that they do not merely reflect societal norms, values and ideologies but also serve to constitute them, as part of a complex and constantly reflexive relationship" (Lupton 1994: 26). The Balm in Gilead's work with the Black Church provides further understanding and legitimization to the notion of an ascribed AIDS identity. Understanding how the Black Church and the larger Black community view drug use, homosexuality, and sexuality and why they view it so better enables an organization like The Balm in Gilead to address the issues associated with HIV/AIDS that have prevented many Black Churches from taking action.

The Balm in Gilead works to put emphasis on AIDS as an *illness*, an illness to which, Parsons might argue, people have no control over. Canon Williams believes that The Balm also works to take the emphasis away from, "how they became infected." It is also important to mention that by addressing homosexuality, sexuality, and drug use, The Balm is showing that there is a place for such discussion within the Church. As I touched upon above, The Balm works to eradicate the stigma associated with AIDS and address the Black Church's particular perspective of the AIDS identity. Through this work, The Balm helps churches to put their Christian duty of love and acceptance over their desire

to distance themselves from those suffering from AIDS by educating the Church about the “AIDS facts,” the topic of the next chapter.

Chapter 5:

Framing for the Church:

AIDS 'Facts'

"Fact, n, happening; actuality; truth; reality."

- *The New Webster's Dictionary*

Introduction:

Time and again, many of the clergy and activists whom I interviewed suggested that "sticking to the facts" about HIV/AIDS makes the subject a less delicate matter and thus more appropriate for the context of the Black Church. When I asked Pernessa Seele how The Balm in Gilead addresses both homosexuality and drug use within the Black Church, she responded, "We address the two by giving people facts. You know, providing churches [and] providing church folk with facts, and helping them to get past their fears and get past their own denial of the presence of HIV in their family. The presence of HIV in their church helps the process" (Seele).

The Balm in Gilead does not produce AIDS facts, but presents or frames AIDS facts obtained from medical establishments for its target audience: the Black Church. For The Balm in Gilead, the framing of the fact is just as important as the fact itself. There are two types of facts that The Balm in Gilead addresses: facts about AIDS and facts about the Black Church. The value of "fact" and fact production cannot be underestimated in relation to AIDS. Sociologists Latour and Woolgar (1979: 23) write, "An important feature of fact construction is the process whereby 'social' factors disappear once a fact is established." These social factors are beliefs about homosexuality, drug addiction, and other taboo topics associated with AIDS. Focusing

on facts appears to take AIDS out of the realm of the "social" and into the realm of the scientific, something that is not easily contested and thought to be above cultural notions of stigma and prejudice. This chapter will discuss the social construction of medicalized facts and how they affect perceptions about AIDS. In addition, this chapter will focus on how contested and controversial AIDS facts are reframed to be appropriate for the Black Church.

As I discussed in the previous chapter, AIDS is a social construct, and the ways in which AIDS and facts about AIDS are constructed dictates various aspects of the societal response to the disease. Facts about AIDS are produced by organizations such as the World Health Organization and The Centers for Disease Control and Prevention. These AIDS facts are taken from health organizations and subsequently filtered and reproduced for the Black Church by The Balm in Gilead. Pernessa Seele uses her knowledge of perceptions and beliefs about AIDS and the responsibility of the Black Church, and presents 'facts' with these beliefs in mind.

As I have previously mentioned, facts, information, and knowledge are key to addressing HIV within the Black Church. The Balm does not just provide the "facts" about AIDS; it presents these facts in a very particular manner, which leads to the question: who is in charge of the production of facts? This chapter will trace the path of fact production, first addressing the theoretical construct of a fact and how it fits into the larger discussion of the sociology of knowledge – discussing how facts are created and re-created based on their relevance to a particular audience. Focus will then be placed on the authority of medical science – how medical institutions are trusted to be knowing bodies, and how those institutions influence AIDS discourse and the production of AIDS

facts. Finally, this chapter will discuss how The Balm in Gilead takes these facts and reframes them and, in the process, reframes preconceived notions about Black sexuality and the role of the Black Church in AIDS discourse.

The Social Construction of Science and Medicine:

According to Emile Durkheim (1950/1982) sociology is the study of social facts. Sociologists try to uncover social facts and understand their relationship within the larger framework of society, especially within its institutional structures. For example, Durkheim's (1951/1979) comparison of suicide rates between Protestants and Catholics yielded a conclusion that the institutional structure of Catholicism had an influence on keeping suicide rates low among Catholics[55]. Durkheim wrote *Suicide* to justify the need for sociology as a discipline that understands and legitimately studies the social trends among actors within society and the roles that social institutions – as they produce social norms – have on the behavior of actors. According to Durkheim, the suicide rate is a social fact, a collective reality that all could agree on and was demonstrated by scientific evidence. Thus, a fact in and of itself is not as important as the societal response to the fact and who we, as a society, trust as the 'fact makers.'

Science:

The previous chapter discussed both the social and cultural constructions of knowledge. This section will examine the construction of science and scientific facts. Recognizing the impact that culture has on the production of scientific facts, Max Weber

[55] Durkheim believed that greater feelings of anomie and less solidarity among Protestants as a result of the promotion of a more personal relationship with God lead to higher rates of suicide among Protestants.

stated that, "the belief in the value of scientific truth is not derived from nature but is a product of definite cultures" (quoted in Merton 1962b). Early in the discipline's history, sociologists not only tried to apply scientific methods to the study of society, but also recognized the application of sociological principles, theories, and methods to the study of the sciences. Parsons noted, "Even if discovered by chance, the consequences of a discovery are thus a function of the way in which it fits into the structure of existing knowledge, and problem-structure" (Parsons 1962: 9). Parsons noted the importance of the sciences as functional, knowledge producing institutions within society. It was not until Bruno Latour and Steve Woolgar's *Laboratory Life*, however, that the social context in which scientific discoveries are made was examined sociologically. In this text, Latour and Woolgar write that they are concerned primarily with how scientific knowledge and facts are socially constructed and focus on the "process" used to make scientific observations and discoveries (1979: 32).

Latour and Woolgar argue that prior to their work, scholars tended to uncritically analyze science focusing primarily on their discoveries. Latour and Woolgar stress the importance of understanding the scientific community gatekeepers to scientific knowledge and facts. These scientists create "science" by creating scientific facts in dialogue with other fact producers. As a result, they argue, that scientific facts – in essence, science – are produced, or constructed. Latour and Woolgar (1979) maintain, social scientific understandings, and particularly that of sociology, of scientific discovery and activity were lacking. Writing several years before Latour and Woolgar's

"anthropology of science"[56], Merton explains that sociologists' preoccupation with social ills such as racism, poverty, education, etc. has led sociologists to overlook the actions of scientists and "science as an evolving social institution" (Merton 1973: 173), with "institutional norms" and rules (Merton 1962a). But ultimately, Merton contends, science is just as interdependent on other social worlds, such as the economy, education, or religion, and can be just as easily influenced by them (Merton 1973).

Scholars, anthropological and sociological, who study the social aspects of science have found there to be a unique culture and even community – with its own sets of rules and values – among scientists. And the production of a scientific fact has to be accepted by, and approved by this community[57]. Conrad and Schneider (1992) write, "Cloaked in the mantle of science, medicine and medical practice are assumed to be objective and value free. But this profoundly misrepresents reality. The very nature of medical practice involves value judgment. To call something a disease is to deem it undesirable" (249). Emily Martin explains, "[t]he establishment of findings in the laboratory as facts accepted by the wider scientific community might turn out to be in large part a social process, a process of gaining credibility from a group of peers through

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[56] Though a noted sociologist, Latour, and his co-author Woolgar do not provide a sociological analysis of science, as has previously been analyzed by Merton; instead, they rely on a more anthropological approach in their studies. They write, "[w]e are not concerned with a sociological analysis in the functionalist tradition which tries to specify norms governing scientists' behavior" (1979: 32).

[57] Bernard Barber's (1962) essay "Resistance by Scientists to Scientific Discovery," analyzes the difficulty that scientists have in accepting some scientific facts as truths. Regardless of grants awarded, publications, and the validity of methodologies used, scientists are, themselves, often skeptical of scientific discoveries. Barber, emphasizing the social nature of science, writes that everything from religious ideas to professional specialization, seniority, and even the prestige of schools (either where the research was conducted or where the scholar attended) influences the acceptance of scientific discovery.

means given legitimacy in the scientific community: scholarly publications, successful grant application, laboratory work, more publication, and so on (Martin 1994: 6). Within scientific communities, everything from the nature and importance of one's scientific discoveries, and even the role of "scientist," are all dependent on one's peers (Merton 1962a: 455). There exists "strict boundaries around who can legitimately speak about scientific knowledge… [for example] drastically negative sanctions await scientists who appeal to the general public for an opinion about their research before seeking certification by professional peers" (Martin 1994: 5).

Scientific findings are heavily influenced by the social worlds in which they are produced, and, as such, scientific ideas are shaped by cultural norms and beliefs (Martin 1994). Within medical science, illnesses have been described using the military terms of "invading" the body (Martin 1994; Sontag 1989). For example, "we can also understand the complex religious, moral, economic, and social grounds on which families accept or reject the use of genetic knowledge about a growing fetus" (Martin 1994: 7).

In the end, scientific knowledge and "facts" are simply constructed. Paula A. Treichler writes:

> One group of influential papers can significantly shape subsequent citation patterns, fix nomenclature, and stimulate or close off particular avenues of research… This may include the power to influence acceptance or rejection of papers for publication, the shape of the language of someone else's publication, to determine the speakers and formats of conference sessions, and to interpret the significance of research for other scientists and the media; the effect is not only to help or hurt individual scientists but to set a gold standard for future discourse. (1992: 76-77)

Ultimately, a fact becomes something that has been published in an article (Latour and Woolgar 1979). These facts about "the natural world" as constructed by scientists, are filtered, and then "trickle down" to other professionals or the public. Martin writes,

"In the filtering or trickling process, scientific knowledge, it is often feared, becomes distorted, partial, and misleading" (Martin 1994: 5). Facts are created in such a way that they appear beyond any historical and social influence. As a result, they are "beyond the scope" of normal sociological interpretation (Latour and Woolgar 1979: 105); and of course, medical findings fall within the realm of scientific findings. The following section will briefly discuss the authority that medical practitioners have in the creation of medical scientific facts.

Medicine:

As "scientists," medical doctors and researchers are trained in the "biomedical model" (Lorber 1997) and apply scientific techniques to the study of medicine, and scientific findings "eventually become part of the medical tradition" (Ben-David 1962: 307). Medicine and its attendant personnel and organizational structures change in accordance with societal views of medicine, perceptions of health, and even "cultural assumptions" (Martin 1987: 27). As described in the previous chapter, understandings of illness, health, etc. are contingent on the wants and needs of a particular community at a particular moment in time. People charged with caring for the ill – whether witch-doctors, spiritual healers, midwives, or medical doctors – have been around for thousands of years. As societies increased in size, however, so too did the scale and scope of diseases and epidemics plaguing them. Increased contact with others, especially through trade, increased societies' exposure to deadly diseases and illnesses, the most devastating example of which was the European arrival in the Americas in the late 15th century (Porter 2003).

Yet despite the increased vulnerability of societies to disease and illness, regard for medical doctors increased over the past two and a half centuries. Conrad and Schneider (1992) state, "The plague and leprosy had nearly disappeared. Smallpox, malaria, and cholera were less devastating than ever before. These improvements in health engendered optimism and increased people's faith in medical practice" (13)[58]. During this time, respectability for those perceived to be on the fringes of medical science (such as witch-doctors and spiritual healers) decreased (Porter 2003). The American Medical Association convinced politicians "to restrict medical practice" (Conrad and Schneider 1992: 13), so that only licensed medical officials could legally practice medicine. Restrictions on medical practice were reinforced around the turn of the 20th century with the Flexner Report.

The Flexner Report, also referred to as *Carnegie Foundation Bulletin Number Four*, was written in 1910 by Abraham Flexner and was funded by the Carnegie Foundation. This report called for an increase in educational standards and more selectivity in admissions and graduation. The tougher standards that were a byproduct of the Flexner Report made obtaining a medical degree significantly more difficult and expensive. This increased the level of "prestige" within medicine because only the "smart" and/or wealthy would be admitted to medical school (Starr 1982).

Also, at the turn of the century, something else truly extraordinary occurred: doctors were called upon to care for the healthy. Starr (1982) argues that as medical technology advanced people began seeking medical treatment to prolong life and to

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[58] Conrad and Schneider (1992) maintain that these changes were probably do to increase standards of living – bathing, nutrition, sanitation – and not advancement in medical science.

prevent illness from occurring, as opposed to treating people after they had already become ill. According to Starr (1982), "modern medicine is an elaborate system of specialized knowledge, technical procedures, and rules of behavior" (3), and as a result, as society became more health conscious and health oriented, the authority of doctors and medical professionals increased; doctors were viewed as trusted producers of health knowledge and facts who had a "claim" to this authority. Starr defines authority as, "the possession of some status, quality, or claim that compels trust or obedience" (1982: 9). Doctors are given an immense amount of authority because of the value we place on medicalized knowledge (Starr 1982). Starr (1982) states: "[Medical] practitioners come into direct and intimate contact with people in their daily lives; they are present at the critical transitional moments of existence. They serve as intermediaries between science and private experience, interpreting personal troubles in the abstract language of scientific knowledge… The very circumstances of sickness promote acceptance of their judgment" (2-4).

In Western society, doctors and other health care professionals have a claim to medical knowledge, giving them cultural, economic, social, and symbolic capital (Lane 2000). This authority does not allow for others to legitimately question their authority, not even their clients (Starr 1982). With this authority came strict requirements as to who is 'qualified' to be a health practitioner and dispense medical knowledge and facts (Ehrenreich and English 1983; Katz Rothman 1991; Porter 2003; Starr 1982). Doctors with four years of undergraduate, four years of medical school, and additional years of specialized residential training – as recommended by the Flexner Report – became the trusted producers of medical knowledge and the producers of facts, to which not

everyone had access. This caused societal dependence on doctors, increasing the authority they have over us as individuals and the political influence they have within society (Starr 1982). Science and medicine have a privileged status within society, and as a result, "medicalization is one of the most effective means of social control (Pitts 1968: 391).

As mentioned in Chapter Four, medical knowledge and facts are products of the culture and time period in which these facts were created. Steven J. Peitzman (1992) has observed, "Disease begins with perceived symptoms. And each generation of physicians has found ways to explain – and in that sense control – the fear and uncertainty such symptoms may provoke. The pain and dysfunction may not have changed over time, but the framework within which they are explained has changed with succeeding generations" (3). The ways in which medical scientists and practitioners perceive the body is heavily influenced by social norms and beliefs, and this has most often been seen in the perceptions of the female body[59]. For example, Emily Martin's *The Woman in the Body*, details the "medical metaphors" used in describing the female body and reproduction. According to Martin (1987), women's bodies were examined in relation to men. She explains how as early as the fourth century women's reproductive systems were considered the same as men's but were described as internal to the body; men's reproductive anatomy was on the outside.

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[59] The same stereotypical roles assigned to gender differences in the sciences and medicine have also been applied to the study of race. White men were, historically, seen as the perfect human specimen, and the model of man – think Leonardo's Vitruvian Man, or even *Henry Gray's Anatomy of the Human Body*, where White men were the "models." Historically, "scientific racism and scientific sexism both taught that proper social relations between the races and the sexes existed in nature" (Schiebinger 1999: 24).

Historically, medical science has portrayed the female body (and in essence, women) as unstable, with women having increased possibilities of hysteria and mental illness as a result. For example, completely confused by the female reproductive system, doctors believed that menopause meant the end of not only women's reproductive lives, but also their womanhood. For example, Anne Fausto-Sterling quotes a medical doctor as saying: " '[t]he vagina begins to shrivel, the breasts atrophy, sexual desire disappears… Increased facial hair, deepening voice, obesity… coarsened features, enlargement of the clitoris, and gradual baldness completes the tragic picture. Not really a man but no longer a functional woman, these individuals live in the world of the intersex'" (1999: 169). This was not simply the case with menopause, the entire reproductive process is gendered. Emily Martin's essay, "The Egg and the Sperm," (1999) explains that even in discussion of reproduction, stereotypical roles of passive woman (egg) and aggressive man (swimming sperm) are assigned to discussions of the sperm and the egg.

These cultural beliefs about women and the human body have greatly influenced the practice of medicine, and have even helped to reinforce stereotypical gender roles – but with a price. Judith Lorber writes: "In the United States, women patients with symptoms of heart disease are treated less aggressively than men patients… Even though coronary heart disease is the major cause of death in the United States, women are less likely than men to be routinely tested for cardiovascular symptoms and more likely to suffer unrecognized heart attacks" (1997: 44). Lorber also found that women ordered more mammograms and Pap tests for female patients, younger male gynecologists were less likely to perform cancer screenings than their female and older male counterparts,

and female physicians were more likely to perform cholesterol testing on their female patients than were male physicians.

In the section above, I briefly provided examples of the instances in which cultural notions of gender influenced the ways in which medical practitioners dealt with medicine and the body. Importantly, these cultural notions even affected how health was perceived and the ways in which scientists considered the body and sicknesses; for example, menopause went from being a 'sickness' to a normal functioning of the body. Similarly, cultural notions of deviance greatly influence science and medicine – not only the ways in which cultural understandings of AIDS were constructed (as described in Chapter Four), but also in how scientific AIDS facts were created.

AIDS Facts:

As described above, Latour and Woolgar argue that a fact becomes a fact when it, "becomes incorporated into a large body of knowledge drawn upon by others." The relative 'newness' of AIDS as a medical phenomenon makes its analysis and the ways in which AIDS facts have been produced easy to trace. Importantly, they go on to note that, "Consequently, there is an essential difficulty associated with wiring the history of a fact: it has, by definition, lost all historical reference" (Latour and Woolgar 1979: 106). A number of different characterizations exist about AIDS, and these different characterizations suggest "its enormous power to generate meanings" (Treichler 1999: 12). Treichler lists 38 different characterizations that have been made about AIDS, which include:

> --An irreversible, untreatable, and invariably fatal infectious disease that threatens to wipe out the whole world.

> --A creation of the state to legitimize widespread invasion of people's lives and sexual practices.
> --A creation of biomedical scientists and the Centers for Disease Control to generate funding for their activities.
> --A gay plague, probably emanating from San Francisco.
> --A capitalist plot to create new markets for pharmaceutical products.
> --Nature's way of cleaning house (1999: 12-13).

For the most part, AIDS facts have been produced by scientific organizations such as the Centers for Disease Control and Prevention. The following section provides a brief analysis of the "historical genesis" (Latour and Woolgar 1979: 106) of AIDS facts.

Founded in 1946 to combat the spread of malaria, The Centers for Disease Control and Prevention in Atlanta has been at the forefront of preventing the spread of infectious diseases within the United States and abroad. The CDC is an organization under the jurisdiction of the U.S. Department of Health and is composed of health care professionals, though not necessarily practitioners, who monitor the sick and the healthy but do not provide medicine. A small number of scientists, medical doctors, and even sociologists at the CDC were charged with understanding AIDS and how it was spread; through years of research with other health organizations, this collective has developed a number of AIDS "facts." Coming from AIDS "experts" (Patton 1990), these facts are published on the CDC's website and have been distributed to health departments and organizations all over the world (Epstein 1999).

Some of the "AIDS facts" advertised by the CDC discuss how HIV is believed to be spread and confront many myths about the virus. For example, the CDC (1999) contends that HIV is not spread through casual kissing, saliva, sweat, tears, or insect bites. These facts are displayed on the CDC website because, according to CDC officials, "The ways in which HIV can be transmitted have been clearly identified.

Unfortunately, false information or statements that are not supported by scientific findings continue to be shared widely through the Internet or popular press. Therefore, the CDC has prepared this fact sheet to correct a few misperceptions about HIV" (The Centers for Disease Control and Prevention, 1999).

In addition to the "AIDS fact sheet," the CDC also produces the "Morbidity and Mortality Weekly Report" (MMRW), a report that details the incidents of all kinds of diseases and tracks illnesses, as well as informs the public of findings from CDC-funded studies. The CDC and especially the MMWR played a formative role in the creation of AIDS discourse; it was the June 5, 1981 issue of MMWR that described the finding of five gay male IV drug users in Los Angeles who were infected with pneumocystis pneumonia, an extremely rare illness. During a 1982 meeting of CDC epidemiologists, the term "acquired immune deficiency syndrome" was used to describe the new sicknesses they were witnessing among these gay men and a smaller emerging population of heterosexuals (Oppenheimer 1992), although the popular press still referred to this disorder as GRIDS, or "gay-related immune deficiency syndrome." For the first couple of years, scientists at the CDC did not know what they were dealing with, and the only 'fact' that they reported was that people were dying from a rare illness as a result of their weakened immune systems (Shilts 1987). The CDC did not know the cause of their illness, only the identities of those 'infected' with the illness, and thus apparently at risk. They were termed by the media as the 'four H's': Haitians, heroin users, hemophiliacs, and homosexuals. Significantly, it was identities, not behaviors, which were believed to be at risk.

Over time, more became known about HIV as an illness and about those infected with HIV. The more middle-class, non-IV drug-using heterosexuals who had not had blood transfusions or were not of Haitian decent who became infected, the more the CDC had to reevaluate its at-risk criteria. By the mid-80s Haitian was dropped as a "risk factor," and once the testing of blood supplies became the norm, so were hemophiliacs. Even though almost everyone is potentially at risk for HIV, the identities of those associated in the popular mind with the illness did not shift. As a result, many did not see themselves at risk, so organizations had to mobilize to "spread the word" about AIDS. They worked to reframe the facts produced by the "knowing experts" at the CDC and other health institutions with facts that were more applicable to certain communities. The two most basic "facts" about AIDS, however, are who is at risk and who can spread it.

The materials produced by the CDC and other health organizations that centered on how to prevent the spread of the illness involved open and sometimes explicit dialogue surrounding sex and sexuality, drug use and abuse. The conversation about anal, oral, and vaginal sex between women and men, women and women, and men and men involved a very difficult topic for Americans. Additionally, how to have sex safely, and the diagrams on how to apply condoms properly and use dental dams were also hard to address. Oftentimes, this material was written non-judgmentally, which made it appear that it was condoning these behaviors. The CDC suggested:

> To minimize the risk of HIV transmission, IDUs [intravenous drug users] must have access to interventions that can help them protect their health. They must be advised to always use sterile injection equipment; warned never to reuse needles, syringes, and other injection equipment; and told that using syringes that have been cleaned with bleach or other disinfectants is not as safe as using new, sterile syringes. (Centers for Disease Control and Prevention 2002: 1)

Discussions concerning prevention for IV drug users and the use of bleaching kits and free needle distribution is also difficult; for many, any discussion of the ways to prevent the transmission of HIV that may occur from high-risk behavior automatically condones such behaviors. The statement, "they must be advised to always use sterile injection equipment," can be read as an acceptance of illegal behaviors that, according to Canon Williams, many within the Black community have been working to distance themselves from for decades.

Not only is the discussion of the ways in which HIV is transmitted difficult for many, so too is understanding the language and medical jargon used to discuss HIV transmission. There are people who still do not understand how HIV is spread, that Magic Johnson is not "cured[60]", who is at risk, what a T-cell count is, or even the differences between HIV and AIDS. According to Debra Levine, one of the main reasons for the confusion and ignorance of AIDS was uncertainty as to what it was and how it was contracted. She states, "I think it was a lack of knowledge, one. It was a pure

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[60] An urban myth is that former basketball player Erving "Magic" Johnson is no longer HIV+. According to this "legend," Magic Johnson had access, through his wealth and connections, to a drug not yet available to the general public, and has been "cured"—proving for many that there is a cure and that drug companies and the government are holding out and, according to one of my students in my Introduction to Sociology course at the College of New Rochelle's South Bronx campus, waiting for poor Blacks and gays to die before releasing it. The popular AIDS magazine, *POZ,* even featured an article referencing this myth. It quotes Johnson as saying, "I'm not cured by any stretch of the imagination… I don't have any magic drug no one else has'" (POZ 2004: 59). Apparently, this all began with a remark that his wife, Cookie, made in 1997 in *Ebony,* "The Lord has definitely healed Erving" (*POZ* May 2004: 59). This myth about Magic Johnson has been reported in a number of different magazines targeted at the Black community. For example, in 2005, *Essence Magazine* reported it as one of their "Top 5 HIV Myths," along with "Myth #1: HIV and AIDS are the same thing… Myth #2: Knowing who's 'on the DL [Down Low]' will save Black women from HIV… Myth #3: Women can't give men HIV [and] Myth #5 Black Churches aren't doing enough to fight against AIDS" (Wright and Jamaralli 2005).

lack of education. I think also you have people who are very unclear about how they think prevention and education should go" (Levine). Even now, some still appears to lack an understanding of how HIV is transmitted. For example, Latrice Wactor describes an incident that took place shortly before our interview: "The other day I was away on vacation and there was a woman who was on vacation with me. She resides in Harlem. There was an incident where [staff] went to serve us a drink – we were in Africa, and they went to serve a drink in one bowl and put straws for everyone to drink. She was like, 'Oh no, I can't do that because you know, that's how you get AIDS'" (Wactor, Interview 2005).

In fact, some of these misconceptions and the many myths associated with HIV have emerged from people not understanding the complex medical jargon used to inform the public about AIDS. For example, an excerpt from the 1981 MMWR report discussed earlier, states:

> Patient 1: A previously healthy 33-year-old man developed *P. carinii* pneumonia and oral mucosal candidiasis in March 1981 after a 2-month history of fever associated with elevated liver enzymes, leukopenia, and CMV viruria. The serum complement-fixation CMV titer in October 1980 was 256; in May 1981 it was 32. The patient's condition deteriorated despite courses of treatment with trimethoprim-sulfamethoxazole (TMP/SMX), pentamidine, and acyclovir. He died May 3, and postmortem examination showed residual *P. carinii* and CMV pneumonia, but no evidence of neoplasia (MMWR 1981: 1).

This type of language and scientific jargon makes it difficult for any layperson to understand what this person died of, much less making people aware of the risk factors. In fact, those charged with providing information to the general public, such as newspaper reporters and journalists, often would mistakenly misconstrue facts and information provided by the CDC and other health organizations, providing the public

with incorrect information such as the case detailing the rates of HIV among gay men of color, which will be discussed in more detail later in this chapter.

In *Frame Analysis,* Goffman defines frames as, "definitions of the situation [that] are built up in accordance with the principles of organization which govern events – at least social ones – and our subjective involvement in them" (1974: 10). He explains how people both organize and give meaning to their everyday lives and experiences and how we as individuals within a society organize and make sense of the society around us. We view society through a particular lens or frame and we draw from our own experiences. Goffman states that we react on both a micro and macro level to how things are framed and how we view them from our own individual lenses; this helps us to learn from and interpret the world around us.

As noted in Chapter Three, this discussion of framing becomes especially pertinent within AIDS discourse where, "the construction of 'AIDS knowledge' and the specific educational strategies used to organize and control this knowledge have been mobilized to anchor a new, if dubious claim to objectivity" (Patton 1990: 5). As I mentioned previously, AIDS was originally called GRIDS or gay-related immune deficiency, after the gay men in New York and Los Angeles who were being diagnosed with a weakened immune system. This framed AIDS as a gay disease. Whether it meant finding a cure, providing funding, or even contracting the virus, its name suggests that it was something about which mainstream society need not worry. According to Randy Shilts (1987), it was nearly five years before medical, public health, federal, and private scientific research establishments, the mass media, and in some cases even sectors of the gay community mobilized to prevent the further spread of HIV. Moreover, one of the

main obstacles to the immediate response was the lack of knowledge about the illness. Since AIDS was framed as a White gay disease, those who were not White gay men saw themselves as immune and did nothing to curb the spread of HIV within their respective communities.

There are many contested 'facts' about HIV and AIDS, such as how it is spread, how it can be prevented, what constitutes AIDS, and how one can tell whether or not one is infected. In fact, there is even debate as to whether HIV actually causes AIDS (Null 2002). Scholar Paula A. Treichler (1999) discusses some of the claims made in some of the early literature on AIDS. One book she cites, *AIDS: The Facts*, written in 1988 by a Harvard-educated, medical journalist John Langone states that, "the virus enters the bloodstream by way of the 'vulnerable anus' and the 'fragile urethra'; in contrast, the 'rugged vagina' (built to be abused by such blunt instruments as penises and small babies) provides too tough a barrier for the AIDS virus to penetrate" (1999:17). Not only have these understandings about AIDS and the body changed, but facts are constantly changing because the medical community is learning more about AIDS everyday. For example, on February 11th, 2005, authorities in New York City announced that a rare and rapidly progressing strain of HIV that did not respond to medication had been detected. This new strain, which progresses very quickly from HIV to AIDS, was the topic of a dozen articles in the *New York Times* alone and opened a debate as to how effective medications would be at combating this strain of HIV and how many different strains of HIV there actually were.

Regardless, whoever controls the knowledge surrounding HIV/AIDS controls the general public's perceptions of AIDS. "By repeatedly citing each other's work, a small

group of scientists quickly established a dense citation network, thus gaining early (if ultimately only partial) control over nomenclature, publication, invitation to conferences, and history" (Treichler 1992: 76). The facts we receive on how to prevent HIV and how to live a long life, if infected, even who is the most "at-risk", have all been constructed, for the most part, by health organizations, institutions, and most notably the CDC. Ultimately, "[f]acts are constructed in such a way that, once the controversy settles, they are taken for granted" (Latour and Woolgar 1979: 183). As contested as AIDS knowledge is, for the most part, it is taken for truth and is spread throughout scientific communities as fact.

Thus, the ways in which facts have been framed by health organizations have made much information inaccessible. As this section has demonstrated,

> AIDS is not merely an invented label, provided to us by science and scientific naming practices, for a clear-cut disease entity caused by a virus. Rather, the very nature of AIDS is constructed through language and in particular through the discourses of medicine and science; this construction is 'true' or 'real' only in certain specific ways – for example, insofar as it successfully guides research or facilitates clinical control over the illness. (Treichler 1999: 11)

Different cultural understandings of AIDS make it pertinent that AIDS be addressed in such a way as to make it accessible to all populations, especially those it most greatly affects (Herdt and Lindenbaum 1992). In promoting AIDS awareness to the Black Church, one of the first steps was to make AIDS 'facts' church appropriate. The Balm reframed AIDS facts, adding to the multiple ways in which AIDS has been and continues to be constructed.

The Balm in Gilead's "Facts":

The information produced by The Balm in Gilead refers to "the basic facts about AIDS" as well as the biblical facts about the obligations that churches have to address HIV. As Seele remarked in a 2005 interview, however, it was facts, or what she calls "misinformation," which prevented the Black community from addressing HIV in the first place. She noted, "Putting AIDS education into a context of prayer, into a context of something that was culturally and spiritually appropriate, opened the door for the faith community to start addressing HIV and AIDS" (Seele, interviewed in McKnight 2005: 72). In a way that was similar to the CDC's creation of AIDS facts, The Balm in Gilead created it own facts about AIDS and the Black Church. These Balm in Gilead AIDS facts were spread through conversation[61], seminars, workshops, and conferences, and through the publication of materials. A number of churches found it difficult to get past the stigmas associated with HIV/AIDS, such as sex, homosexuality, and IV drug use; but churches, along with The Balm in Gilead, found success in focusing solely on two types of facts: the facts of AIDS – how it is spread, statistics, etc. – and the facts of Christianity and the biblical obligations of Christians. As a result, there were two types of "facts" that The Balm addressed in its work, facts about the Black Church and the facts about AIDS. It was those two sets of facts that it reconciled and reframed.

The advice that The Balm gives on working with the Black Church includes:

- Respect the Black Church as the oldest and most influential institution supported and controlled by Black people in the Black community.
- Understand that the pastor is the leader and must give approval for the church to participate in The Black Church Week of Prayer for the Healing of AIDS and all programs involving the church.

[61] Latour and Woolgar (1979) describe how facts are "constructed and disseminated" through conversation (154).

- Understand the significance of Jesus in the life of the Black Church and its members.

> -The Black Church Week of Prayer for the Healing of AIDS 2003 Training Manual (The Balm in Gilead 2003b: 8)

The Balm understands the history of the Black Church, its structure, as well as the beliefs and practices of many of its members. These facts, as The Balm sees it, about the Black Church help them to understand and frame AIDS in such a way as to make AIDS and AIDS dialogue church appropriate; just as The Balm recognizes that there are perceived facts about AIDS and the Black Church, there are also facts about Christianity. Ms. Seele believes that "the role of the faith community is at the core of addressing HIV/AIDS in the African American community" (Seele, interviewed in McKnight 2005: 72). She believes that the Black Church and The Balm share similar goals – to provide guidance, healing, and compassion.

Reframing the Facts:

Much of the initial misinformation about HIV/AIDS can be blamed on the Centers for Disease Control and Prevention, which, along with a number of other health organizations, initially characterized AIDS as a disease of gay White men and IV drug users (Shilts, 1987) – populations the Black Church avoids. Seele maintains that, many still, "believe that homosexuality causes AIDS. They believe that myth, that fact, that lie" (Seele, interview 2005). Seele furthers explains this in an interview she gave with Erica L. McKnight in 2005:

> When we began addressing HIV/AIDS in the early 1980s, misinformation came out of the public health community. We can see the lasting impact of that it was GRID [gay-related immunodeficiency disease], it was a gay man's disease, and it was never going to affect the heterosexual community. All of that initial information that was put into the community still has an impact on the African

> American community… I call that kind of erroneous thinking – which has its root in misinformation – the new mis-education of the Negro. We have recycled the mis-education of the Negro when it comes to HIV and AIDS. (McKnight 2005: 74)

Thus, The Balm in Gilead informs the Black Church through re-educating, removing the misinformation, the sin, and thus, the stigma, by emphasizing the medical aspects of AIDS. This removal of stigma is what Conrad and Schneider (1992) refer to as one of the "brighter" sides to the medicalization of deviance (247).

Goffman (1963) explains how people both organize and give meaning to their everyday lives and experiences, and The Balm helps to provide such meaning. Dr. Moon-Howard notes:

> The Balm in Gilead was one of the first organizations to take information about HIV and AIDS, define it, and put it in a language in which religious leaders and organizations could both understand it and… use it. That was a real important step and they have literature that relates to the local structures so that churches have a context in which to talk about HIV and AIDS with their congregations. (Moon-Howard)

The Balm in Gilead not only frames AIDS facts for The Black Church as a whole, it can also tailor the way this information is framed for specific churches, clergy, and organizations that request technical support.

When asked if AIDS information was aimed at the Black Church by any other organization prior to The Balm in Gilead, Dr. Joyce Moon-Howard, both a board member of The Balm in Gilead and a professor of public health at the Mailman School of Public Health explained that she did not know of any because:

> Scientists have not had the time to try to translate information for consumers and communities. And whether we were talking about churches or schools… there was a real issue about approaching the religious community. There was a real disjuncture there. So Pernessa, with her background in immunology and having worked for the CDC, she wore two hats. She wore a hat as a scientist as well as someone who was well connected and knowledgeable of the Church. It was a

> very unique role. She is a unique person in that she could wear both hats and speak [sic] languages. When she started the Week of Prayer, she was working at Harlem hospital in their infectious disease department. So speaking on HIV and AIDS from that vantage point at that time was very important. She wasn't the lay person talking to the Church and relating to the university, she was, in fact, somebody working in infectious disease, talking to both the scientists in the hospital as well as the religious leaders in the community about these issues.

Not only was information not aimed at the Black Church, it was not aimed at the Black community either. According to Debra Levine, for years after the first cases of HIV were being diagnosed, no one "ever talked to the African American community about prevention activities, we never had programs designed to deal with communities of color and their cultural competency issues or linguistic issues." According to Levine, no one provided the Black community with the facts about AIDS. But Seele firmly believed that before facts can be adequately addressed, awareness of the issue must first be addressed. "Awareness is the first stage. [Seele] spent a lot of time in the early years increasing awareness of the issue and helping the Church recognize that it was something that they had been silent on but that it was affecting both their congregants as well as the community" (Moon-Howard). Thus, the primary purpose of the Black Church Week of Prayer for the Healing of AIDS is for the Church to become aware of the toll that AIDS is taking on the Black community, and The Balm in Gilead provided a "safe space" from which to talk about AIDS. Dr. Joyce Moon-Howard contends:

> Once [Seele] was able to translate the action of prayer as a way that promotes the healing of AIDS, that was something that all religious organizations, leadership, and congregants could participate in and do, and that's what really caused a turning point. What she imparted was that religious leaders and congregants could pray together for the healing of AIDS, then in fact, they have committed an action that could be helpful. And all the Church leaders felt that they could pray… That's the common denominator across all religious groups. Once that occurred, then there was a movement forwards. Because once there was a recognition, then there was movement forward, because people could come

> forward and talk to their religious leaders about whatever was confronting them personally [about AIDS].

According to Tonya Perry, the goal of The Balm is "generating awareness, and awareness to the extent that it's actually impacting behavior change… And that's the challenge. How do you translate that? How do you move from education and awareness to impacting behavior change?"

Pernessa Seele recognized that, "the Church [can be used as] a vessel" (Moon-Howard) to reach large numbers of Blacks with information about AIDS, despite the modes of transmission. But many medical institutions also "haven't necessarily done the best job in getting into the Church" (Moon-Howard), or reaching out to the Black community as a whole. Wactor explains, "I think they're [public health officials are] coming from a whole different perspective, a whole different lifestyle, a whole different ideology than we are."

In addition to homophobia, fear, and lack of knowledge, some churches and other religious institutions simply do not trust the information produced by medical institutions. The Black community has historically mistrusted the medical establishment (Washington 2006), and this mistrust was reinforced when the details of the Tuskegee Syphilis Study[62] were made public. In addition, many Blacks, believe that AIDS is a government conspiracy (Freimuth, Crouse, Thomas, Cole, Zook, and Duncan 2001; Cohen 1999;

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[62] The Tuskegee Syphilis Study, as it is now known (originally titled "The Tuskegee Study of Untreated Syphilis in the Negro Male"), was a project carried out in Alabama on a group of 600 Black men, most of who were injected with syphilis. This study took place for approximately forty years (from 1932-1972) by the United States Public Health Service. This project withheld treatment from these men so that the medical establishment could learn more about the development of the disease. When the story broke out in 1972 and the NAACP won a lawsuit in 1973, the Black community's mistrust of the American medical establishment was deepened.

Thomas and Quinn 1991). In fact, between 2002 and 2003, almost half of 500 Blacks surveyed in a study by the Rand Corp. and Oregon State University believed that AIDS is man-made and was created to "control or wipe out their communities" (Fears 2005: A02); and 15% believed it was created to wipe out Blacks. A majority of the people surveyed believed that the cure was withheld, and almost half believed that the government is using those who take medications as "guinea pigs," which helps to explain why there are so few Blacks who volunteer for AIDS research. For many Blacks, AIDS and Tuskegee have many similarities. They remember well instances of mistreatment and abuse such as occurred in the Tuskegee experiments, suggesting that their fears of government malfeasance regarding the AIDS epidemic are warranted; the conspiracies, myths, and urban legends surrounding AIDS are understandable. Rev. Trumpet recognizes these concerns about an AIDS conspiracy, but she maintains:

> people almost got off track talking about all the theories of why HIV and AIDS exists and where did it start, and the conspiracy, the monkey, or the White gay steward on the plane… The reality is HIV and AIDS is here. The reality is, it's killing people. So now we could spend from now to eternity discussing how we got here, who's responsible, if it escaped out the lab. [But] we got to address the fact that we have to keep people from dying, so we need to talk about prevention, and we need to talk about getting people in treatment and getting people tested so folk know where they stand, which will inform their behavior. Let's hope. Let's hope.

Since many Blacks do not trust medical establishments,

> It's really important that the message come from the Church because, in addition to everywhere else, you still have the segment of the population that needs to hear the messages that… may not hear it in another traditional manner. You have mothers, grandmothers that need the information that they can take back to their families, their communities. And I think the Church may deliver it in a more culturally sensitive way than maybe some other health organization. So, I think it's really important for the Church to educate their community or their congregation about HIV and AIDS. (Wactor)

In addition to providing technical assistance, developing church appropriate and relevant AIDS material is a very important part of The Balm's job. In fact, when asked to describe how Seele develops AIDS material, Dr. Moon-Howard responded: "[Seele] has brought together people in different spheres. She has religious leaders, theologians, and scientists working together to develop a translation of the science information that we have into the context of church and church work. She's brought together experts to help in the development of the materials."

The AIDS information provided within these materials comes from information published by the CDC in publications such as the various AIDS Surveillance Reports and AIDS Facts Sheets, information to which the general public has access. As previously explained, Blacks many not feel as if they have access to this information or feel that this information had any relevance to their everyday lives. In fact, according to Debra Levine, not only did Blacks not have access to the "facts" about AIDS, Blacks also were not in a position to be fact producers. She maintains, "We weren't sitting at the table where policy decisions were being made about how money came down. We weren't sitting on the review boards in the hospitals about patient care and patient confidentiality. We weren't at those tables, not because we didn't want to [be], but just because that's where the power lies" (Levine). By providing facts, The Balm provides information relevant to not only the Church but to Blacks as well. Despite Seele's emphasis on reframing facts about AIDS, she encourages churches to rely on the CDC for additional AIDS information. She states:

> The CDC has a national clearing house and it runs a national hotline. I do not run a national hotline. I do not know all the answers to HIV and AIDS. I do not have all the materials that have been written on HIV; the CDC has. The CDC can provide [answers]; if it is someone who is in Tupelo, Mississippi, the CDC will

> know where that person can go to get an HIV test. I don't have that capability, so if they want to know about treatment education, the CDC are the experts in this. (Seele)

The Balm may not have all of the answers, but it can reframe the answers in a way that is suitable for churches. For example, an AIDS prevention fact provided by the CDC states:

> The proper and consistent use of latex or polyurethane (a type of plastic) condoms when engaging in sexual intercourse--vaginal, anal, or oral--can greatly reduce a person's risk of acquiring or transmitting sexually transmitted diseases, including HIV infection. (Centers for Disease Control and Prevention 1999)

Congregants and church leaders may have found that simply addressing sex without stating the importance of abstinence may go against church teachings. As a result, The Balm in Gilead reframes this information and states:

> Practicing abstinence is one way you will not become infected with HIV. This means that you have made a choice to not have sex – oral, vaginal or anal – with anyone… People who make a decision to have sex should be aware of the risks and responsibilities of both persons to protect themselves and their partner. In this age of AIDS, safe and responsible sex allows people to enjoy God's special gift of lovemaking without putting themselves in danger. (The Balm in Gilead 2001)

Yet, providing this information is not enough, The Balm wants to make Black Churches aware that AIDS is a crisis within the Black community. In *Extending Grace! An AIDS Ministry Handbook* published by The Balm in Gilead, Blacks are provided with relevant AIDS statistics provided by the CDC, The Harvard AIDS Institute and UNAIDS, with the following bullet points including:

- One in 160 Black women is infected with HIV.
- The Caribbean is the second worst affected area in the world next to sub-Saharan Africa. In the Caribbean, AIDS is the leading cause of death among persons 15 to 45 years old. (The Balm in Gilead 2001: 5)

Currently, much of the work at The Balm in Gilead is to produce AIDS awareness through "church appropriate" facts and materials. In discussing how AIDS curricula and material are produced, Seele stated: "It depends on what curriculum it is. It depends on which program it is. Sometimes I bring in a group of consultants. Sometimes I do it myself. Sometimes I have people on staff do it. It really depends. It depends on what the subject area is and who we are talking with" (Seele).

With every book, video, and piece of resource material that The Balm produces, work is done to make sure that it has created suitable AIDS information that is educational, informative, and – most important – appropriate. Levine says that producing material and information for Blacks is like producing material for any "subpopulation. You have to design the curriculum" (Levine). The development of this specially produced curriculum was key to the success of The Balm because "it used a language that communities of color were familiar with. It used language that our faith-based leaders were comfortable with. It talked about prayer. It talked about self-worth. It gave people the option to talk about abstinence only vs. using condoms. It worked with them around their theology" (Levine). Dr. Moon-Howard elaborates:

> For example, The Balm developed a Sunday School Curriculum educating youth about AIDS. [The Balm] brought together a group of experts who spent more than a year actually bring[ing] together the information, so there were experts in both theology and Christian education in research design that took a look at and worked with the process and pre-tested it and all of the regular ways you set up developing curriculum and making sure that it's appropriate for the age group. All of the major religions that would be using the curriculum were involved so it wasn't like The Balm, an organization encapsulated in itself, decided to write a curriculum.

As briefly addressed earlier, The Balm produces facts not only for the Church in general or for particular congregations. It can also tailor information specifically for a

group setting. According to Rev. Ware, Director of Church and Community Mobilization for The Balm in Gilead, "[it] depends on the group. You go in, you get a feel for the group. It depends on how long I'm with the group… Because everybody's at a different place and I try to keep that in my mind when I am talking to groups. A little bit to this group and a little bit to that one and bring them all together and they all laugh." Not only are individual churches within the institution of the Black Church at "different place[s]" in their understanding of HIV and AIDS, but so are individuals within the churches. With this in mind, by framing AIDS facts for specific churches and even individuals, Seele will come closer to reaching her goal of having AIDS ministries in all Black Churches in the United States and all "African American youth… aware and knowledgeable about HIV" (Seele).

Regardless of how well-intentioned Seele and her staff are in reframing AIDS information and facts, they can only reframe the given "facts," even ones that are contested. In the 2001 *Extending Grace!,* listed in a section entitled "Facts About AIDS" under the subheading "Looking at the Statistics*,"* it states, "In many major urban centers across America, as much as thirty percent of Black gay men are infected with HIV" (2001: 5). Much like in the early days of the AIDS epidemic, this reframed "fact" is not a fact at all but a widely held myth perpetuated by the media and distributed as "fact" by AIDS service organizations across the country. According to the footnote at the bottom of the page, the data provided in this section came from the CDC, The Harvard AIDS Institute, and UNAIDS. This statistic is in reference to a study conducted by the CDC of gay men in major U.S. cities. These men were approached in bars and clubs and it was found that out of the ones who agreed to participate in this study, around 30% were HIV

positive. It became widely publicized that 30% of Black gay men were HIV positive, when in fact 30% of the men that were *sampled* for this study were HIV positive. This statistic has been touted as truth and may have helped to fuel the rage over "men on the down low" and the possibility that these infected "bisexual" Black men are having sex with these positive Black gay men, helping to increase the rates of HIV among Black women. As a result, those trusted to produce or distribute facts sometimes get the facts wrong. I am sure The Balm was well intentioned in providing information, and it is especially meaningful because those numbers, even if they are false, are startling. But just as important, though it could also increase homophobia and reproduce the belief that AIDS is a gay disease by including statistics on Black gay men alongside statistics on heterosexual women and men, The Balm emphasizes that they are part of the Black community and should not be overlooked.

Conclusion:

"I think over these past 25 years, churches have grown in their understanding and their educational knowledge about HIV, and that has informed them to become part of the solution, not part of the problem" (Seele). Ideally, The Balm in Gilead would like the Church to, "take the information that [it] provides and share with the congregation and then let it expand into the community, [the] community around the Church" (Ware). Many Black Churches already have ministries that deal with everything from youth, to alcoholism, to prisoners, to general health ministries; an AIDS ministry is different, however, because of the facts about HIV and how HIV is transmitted. The Balm in Gilead has become trusted to educate churches about these facts and information about

AIDS, just as The Balm trusts the Church is to educate congregations and whole communities. What Seele has accomplished by reframing these AIDS facts is noteworthy:

> because other than the fact that [The Balm is] an expert in their field, an HIV ministry is something new and unique to faith-based organizations, and I think one thing [about] having a Balm in Gilead is, what [Seele] has done is she's been able to address the issue of HIV and AIDS in a faith- based setting or in faith-based institutions that traditionally would not listen, did not want to hear. She was able to pull together these heads of these huge faith-based institutions to make them realize there is a problem in the Black community around HIV and AIDS. (Wactor)

According to Seele, these churches are free to adapt and present these facts in whichever way they chose, just as long as the "facts," as originally produced by medical establishments, are presented. Then again, as shown above, The Balm cannot produce just any AIDS information. The Balm is constrained in how it can reproduce AIDS facts for churches by two key things: 1. the illness itself and 2. the morals and values of The Black Church.

As this chapter has shown, The Balm is not a fact producer; I argue The Balm is a "fact reproducer." The Balm in Gilead gets its AIDS information from the CDC and the World Health Organization. The Balm in Gilead then reproduces culturally appropriate AIDS facts that resonate with its target audience, the Black Church.

Though medical institutions are not known for producing the most accurate facts, they are still trusted to do so. Paula A. Treichler (1999) cites a number of different 'facts' produced by scientists in the mid-80s about AIDS:

> --AIDS could be *anything*, considering what homosexual men do to each other in gay baths.
> --Heroin addicts won't use clean needles because they would rather get AIDS than give up the ritual of sharing them.

> --Prostitutes do not routinely keep themselves clean and are therefore 'reservoirs' of disease.
> --AIDS is homosexual; it can be transmitted only by males to males.
> --AIDS in Africa is heterosexual but unidirectional: it can be transmitted only from males to females.
> --AIDS in Africa is heterosexual because anal intercourse is a common form of birth control there. (16)

Though, for the most part, these misconceptions have been reevaluated. As I mentioned briefly above, there is still much about HIV that doctors and researchers do not know. For example, the March, 2006 edition of *Harper's Magazine* features the article, "Out of Control: AIDS and the Corruption of Medical Science." Though highly controversial, this piece by Celia Farber details the story of Joyce Ann Hafford, who was diagnosed as HIV+ shortly after finding out that she was pregnant and was immediately put on an HIV drug regimen to prevent the spread of HIV to her unborn child. This regimen ended up killing her. Even more tragic – she did not have AIDS. Neither she nor her doctors were aware of the false positive results that can occur from pregnancy. Farber's article then goes into a lengthy discussion about how HIV does not necessarily cause AIDS and that HIV tests are not necessarily accurate.

The morals and values of the Black Church, as a religious institution, are the second constraint that The Balm has to work within in order to create AIDS awareness among these churches. As this chapter has shown, The Balm has to produce material that is appropriate for the Church and fits within its religious beliefs. I found that this most often occurred with discussions of the modes of HIV transmission. I explained how church and ministry leaders felt uncomfortable discussing drug use, and especially homosexuality and sexuality. Realizing this, The Balm does not encourage church leaders to preach anything to which they may object. For example, though abstinence is

the most effective method preventing HIV, teaching "abstinence-only" is ineffective; in fact, a 2005 study found that, while students reported a decrease in their intention to have sex, they also reported a decrease in their intention to use a condom when having sex (Borawski, Trapl, Lovegreen, Colabianchi, and Block 2005). Hernandez and Smith (1990) found that abstinence-only education did not influence behavior one way or the other. The danger of abstinence- only education is that young (and older) people are not taught how to adequately protect themselves during sex (Starkman and Rajani 2002; Gochros 1988), yet religious institutions continue to preach this form of protection. For instance, Ms. Griffin of Berean Baptist Church's AIDS ministry says: "My premise is that we know what the scripture teaches and we don't guess what the scripture teaches. We say abstinence first, and if they are *involved*, they need to know that their behavior is killing them. That's the next thing that we say, because just saying abstinence and not telling them about it—being protected—is not helping the situation" (Griffin).

The constraints of the illness and values of the Black Church allow for very limited ways in which AIDS can be addressed, which affects the probability that The Balm would be able to produce AIDS facts and convince churches to educate their congregations based on these facts. As this chapter has shown, The Balm in Gilead must work to reconcile the facts about the illness and its transmission with the religious and moral values of the Black Church. The facts about AIDS and HIV prevention, however, inhibit an open and frank discussion of AIDS and HIV transmission. Yet, on a more positive note, by addressing the risk factors for HIV and AIDS churches will have to address the myths; they will have to address homosexuality, homophobia, drug use, and risky sex. Griffin's "premise" is that you "stay with the facts" and address AIDS just as

you would any disease or illness. You don't want to "turn people off" to the facts by focusing on the divisive aspects of the disease (Griffin), but by addressing the facts, these churches are also challenging the myths.

Ultimately, as this chapter has shown, facts can be produced and reproduced as many times as necessary to become relevant to the producer's desired audience. A particular fact may not be perceived as a truth to a particular audience if this fact is not framed for that audience. This notion is especially applicable to medical institutions because we make health decisions to increase our longevity based on medical facts. In this case, AIDS facts are being re-created to be relevant to the Black Church. By reframing AIDS, The Balm is empowering the Black Church not only to address AIDS, but also to address the social issues associated with AIDS. For example, The Balm is also reframing perceived facts about *sexuality*, showing that sex and sexuality can be openly discussed within the Church and showing that that sex does indeed have a place within the teachings of the Black Church. By addressing AIDS within the context of the Black Church, The Balm is emphasizing the role that the Black Church could play as reproducer of AIDS facts for the church's congregation and community.

In the end, The Balm in Gilead focuses on the scientific and medicalized "facts" of AIDS as a disease. The presentation of these facts emphasizes the belief that The Balm has in medical science as a neutral, value-free discipline. The Balm believes that by re-producing and disseminating these facts, they will be free of the value judgments that prevented Black churches from addressing AIDS in the past. The trust that The Balm in Gilead places in these medicalized facts is an example of the dominance that medical science has and the perception of the sciences as the best way in which to reach

people. The Balm does not take into account that these scientific AIDS facts were created with the similar societal biases and understandings of deviance and morals as exist within the larger society. The Balm does not take into account (possibly due to Seele's former occupation as an immunologist) that by re-creating AIDS facts to be church-appropriate, they are 1. participating in the legitimatization of medicalized knowledge, 2. emphasizing the malleability of medicalized knowledge and facts, and most importantly, 3. helping to "shape the discourse on AIDS (Treichler 1999: 18).

Chapter 6

Selling Disease:

Social Marketing and Its Application to

AIDS Awareness within the Black Church

Introduction:

As shown in the previous chapter, a tension has arisen between the morals of the Black Church as a religious institution and facts about AIDS as an illness. The Balm in Gilead creates AIDS information in a way that reconciles these different perspectives. Then again, The Balm in Gilead cannot simply say, "it is in your best interest to address AIDS;" its AIDS information has to resonate with religious themes. For The Balm, it is important that churches be made to feel as if they are naturally receiving AIDS information. As such, The Balm has to make it seem as if the material it is producing and the means in which the material resonates with the Church is not deliberate. This information has to be carefully framed within a moral narrative. The technique by which The Balm in Gilead encourages churches to address AIDS is through social marketing.

Social marketing is most often used to introduce or create a social problem. Social marketing is used to address many of today's problematic health issues – from drug use to weight-loss to smoking cessation – and to advertise medicalized facts. Social service organizations utilize social marketing techniques to develop campaigns aimed at a particular group, or a target population, to convince them to adopt a behavior change (Andreasen 2005). Such marketing campaigns have been developed to provide AIDS education, usually by either convincing people to participate in reduced-risk behaviors or

to help remove the stigmas associated with AIDS. For example, Gay Men's Health Crisis (GMHC)[63] utilizes a number of different HIV/AIDS social marketing campaigns aimed primarily at gay men, and increasingly, gay men of color. These campaigns consist of everything from developing interactive websites to producing educational commercials and billboards. One such campaign organized by GMHC is The House of Latex (HOL). Started in 1989, the HOL addresses HIV/AIDS within the ball/house community[64]. GMHC originally "tabled" balls, setting up an information table with condoms, dental dams, lubricant, and other safer sex paraphernalia, as well as brochures and pamphlets. GMHC did not find much success in distributing information, however, until housemothers and fathers approached them about starting their own house. The HOL consists of GMHC employees and a number of members of the ballroom community who work together to organize balls and campaigns to appeal to this community. This group emphasizes safer sex within a context that participants in the ballroom community can understand and appreciate.

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[63] A number of gay men gathered in Larry Kramer's apartment in 1981 to address the publicity surrounding the "gay cancer." This lead to the development of an AIDS hotline, the first in the world, and then, in 1981, GMHC became an official organization. GMHC was the first AIDS service organization that provided advocacy, care, education, and service to those suffering from HIV and AIDS.

[64] Balls date as far back as 1879, with the first being at the Hamilton Lodge in Harlem. Balls are large parties or events attended primarily by Black gay men who are part of "houses" or "clubs" (a type of family structure), at which they gather to perform dances, or "vogue," to compete for prizes and trophies. Located in most major U.S. cities, houses consist of a mother and/or father, a house leader, and house members – kids. Houses tend to be named after designers or brands/labels trends, such as the House of Mizrahi, the House of Essence, and the House of Chanel. Though popular among gay men and lesbians of color, the ball community was primarily underground until Jennie Livingston's 1991 documentary, *Paris is Burning*, introduced outsiders to this community.

For social marketing campaigns to be successful, social marketers such as those at the HOL must have an understanding of the target population and of the unique issues and problems facing this population. This formula has proven to be especially relevant to AIDS education. The HOL utilizes similar social marketing techniques as The Balm in Gilead. They both frame AIDS as a social problem and market AIDS information to a community in a way that complements its own social constructions of AIDS, thereby "meeting people where they are" with facts and information pertaining to their lives and experiences.

This chapter will address how The Balm in Gilead utilizes social marketing techniques in the framing and distribution of its translated AIDS information. I use social marketing literature to examine how The Balm in Gilead works with Black Churches, and the different techniques it uses to promote AIDS awareness to the Black Church while expanding upon traditional marketing techniques in order to reach its key demographic. Like all social marketing campaigns, The Balm not only markets a behavior change, but also an attitude and a perception change. I will also address how The Balm makes AIDS a social problem for The Black Church by using advertisements to "sell" its product and analyze the different ways in which AIDS is marketed to the Black Church.

The Balm in Gilead provides AIDS education and awareness that resonates with Black Churches by utilizing social marketing techniques, whereby AIDS and the knowledge surrounding AIDS becomes a commodified product that can be advertised and sold. I will also detail in this chapter the different ways this commodified product has become profitable. Finally, there is an examination of how The Balm in Gilead 'sells' its version of church-appropriate AIDS knowledge, and markets it in a way that

befits the Black Church's morals and values. I will first provide a background of the field of social marketing and its relevance in AIDS discourse.

Marketing Social Behaviors:

Marketing and advertising, in general, require a great deal of understanding of the social world, relationships, structures, and the meanings associated with ideas and products. Marketing also identifies the needs of a particular community, organization, or company, and uses marketing techniques to develop goods and services that are distributed to that community. Once the community and the best ways to reach them are identified, advertisements—or the selling of symbols that represent ideas and emotions – are used to convince the audience of the value of the product. As a result, Cortes (1999) called advertising, a "paid, mass-mediated attempt to persuade" (145). Ultimately, the goal of marketing and advertising is to understand a target community well enough to get its message across effectively, using campaigns and advertisements that will be persuasive and thereby promote a message, agenda, or a product.

According to *Marketing News*, the newspaper of the American Marketing Association (AMA), the official definition of marketing is, "the process of planning and executing the conception, pricing, promotion and distribution of ideas, goods and services to create exchanges that satisfy individual and organizational objectives" (cited in Fine 1990:1). For example, in order to reach potential consumers within communities of color, marketers have identified the needs of these different communities and have utilized different forms of media to attract and market to these groups. Anthony J. Cortese examines how minority groups are influenced by social structures through their

depictions in the media. He states that marketers understand how, "social structure and social processes affect individual attitudes and behaviors" (Cortese 1999: xii), and he examines media and advertising and how they both influence the behaviors of minority groups and even attitudes *towards* minorities. Goffman found the same to be the case in relation to gender perceptions in his 1979 classic *Gender Advertisements*. At the core of marketing is the sale of an idea that can be made available to a market's needs and wants (Kotler and Andereasen 1996).

> All marketers are in the profession of creating, building, and maintaining *exchanges*. For example, a customer pays $1.99 and gets a slice of pizza; a driver buckles up a seat belt and gets peace of mind; or a mother in Bangladesh attends a workshop on diarrhea management and learns how to save her children from dying of dehydration. Because exchanges only take place when a target audience member *takes an action*, the ultimate objective of generic marketing is to influence behavior. (Kotler and Andreasen 1996: 388-9)

For example, marketing techniques are used to sell the idea of looking good in a pair of Levi's, or of drinking a can of Pepsi, eating at Red Lobster, even attending a particular college. Marketing, through advertisements and viewing, events, etc, makes one consciously aware of a product's existence and of the potential relevance of this product to one's everyday life. Marketers are putting an idea in the target's head where it may not have previously been. The target may not have been thinking about drinking a Pepsi, but Pepsico (the Pepsi Company) wants the target to be thinking about it and, as result, go out and purchase it. Pepsico is advertising the feel and experience of drinking a Pepsi – the target can only go so far with the taste of a beverage. They want the target to believe that the experience will lead them to feel sexually desirable, excited, fulfilled, refreshed, and cool. Marketers want you, as the target, to realize that you have needs that you did not know you had. Social marketers use an approach similar to that of Pepsico in

addressing AIDS. Since the symbolic meanings associated with a product are vital in marketing and promoting ideas, it is easy to see how marketing can be applied to promoting behaviors and change for the betterment of a community. In sum, Kolter and Roberto (1989) view both "ideas" and "behaviors" as the product that is being marketed (1989: 25).

The concept of social marketing, a subset of non-profit marketing (Kotler and Andreasen 1996), has been around for almost 30 years (Weinriech 1999). Community-based organizations such as The Balm in Gilead, private foundations such as The Kaiser Family Foundation, and public health officials such as the CDC and the New York City Department of Health have all utilized social marketing techniques. Weinreich believes that this behavior-oriented form of marketing made:

> use of commercial marketing techniques to promote the adoption of a behavior that will improve the health or well-being of the target audience or of society as a whole. These are the same methods that a company such as Coca-Cola uses to sell its soft drinks – a focus on its consumers, market research, and a systematic process for developing a marketing program. The key characteristics that distinguishes social marketing from commercial marketing is its purpose; that is, the benefits accrue to the individual or society rather than to the marketer's organization. (Weinreich 1999: 3-4)

Similar to marketing a pair of Levi's, where a feeling is associated with the jeans, The Balm in Gilead wants a feeling to be associated with AIDS. The target may not have been thinking about AIDS at church, but The Balm in Gilead wants the target to be. The Balm wants the Church and its congregants to be always thinking about AIDS and always to have it in the back of their minds. Seeing that the Church is aware of AIDS may help the community and the congregations to see AIDS as something for them to be aware of, cautious of, and, as a result, protect themselves from. While many different organizations use social marketing, what distinguishes one from another is the product

being marketed and the packaging used. In the case of The Balm in Gilead, the product is AIDS awareness.

Marketing AIDS:

Social marketing techniques have been especially useful in promoting AIDS awareness and HIV prevention; in fact, the most well known social marketing texts (Andreasen 2005; Andreasen 2001; Kotler, et al. 2002; Weinreich 1999; Kotler and Andreasen 1996; Fine 1990; Kotler and Roberto 1989) address HIV and the challenges that social marketers have in adequately addressing AIDS. Many of these challenges are rooted in material that is neither culturally sensitive nor created with the understanding of a particular group or community's perspective of the AIDS identity. For example, organizations such as the CDC and GMHC, for two decades now, have been utilizing social marketing campaigns to address HIV/AIDS. The CDC's Prevention Marketing Initiative, a program that utilizes the media to assist communities and organizations in improving their HIV prevention and AIDS services, published the 1996 document: *The Prevention Marketing Initiative: Applying Prevention Marketing.* This document helps AIDS service organizations develop and apply social marketing techniques to reach both their target audience and a larger audience.

AIDS campaigns tend to be very mindful not to create stigma and encourage the fear of people who are already infected. Most ads tend to emphasize life, acceptance, understanding – the human characteristics of those infected with HIV. As I addressed in the previous chapter, it was this fear of AIDS, this "FRAIDS" (Franzini 1993), and the fear and stigmas associated with those perceived as spreading it (i.e. gay men and drug

users), that created AIDS stigma (Herek 1999; Herek and Glunt 1988). This stigma has prevented many from seeing the susceptibility that everyone has to contracting the disease. Early media campaigns emphasized the fear that people had of contracting HIV – people were afraid of gay men and lesbians, IV drug users, Haitians, essentially every group that people associated with HIV. The fearful social construction of AIDS, which created the AIDS identity, only served to further stigmatize those infected with HIV and prevented others from seeing their own susceptibility to contracting HIV. This only helped fuel the epidemic. Thus, in AIDS social marketing campaigns, a large part of the focus is on fear, presently freeing oneself from fear – fear of contraction, and fear of those infected – in order to see the control that one has over one's life and health.

More important, these current campaigns also free those already infected from the fear of death – their own death – by emphasizing the long and healthy life that one can have while on medications; and these campaigns also free those from the possibility of infecting someone else or becoming infected if condoms or body fluid barriers are not used. This is a very different approach than social marketers have previously taken with other public health campaigns, and though the approach is different, the message is not: you have the ultimate control over how you live your life; or as the tagline from an old seat belt campaign would say – "your life is in your hands." This is especially prevalent in current anti-tobacco campaigns. Cigarette smoking was once considered mainstream and acceptable; social marketers had to change that perspective to promote smoking cessation – the experiences now being marketed are death, fear, pain and deception. For example, the "tagline" for the new anti-smoking ad campaign by New York City's Department of Health (NYCDOH) service is: "Mike is dying for a smoke," which, like

many anti-smoking campaigns, advertises the pain and fear associated with cancer and the impending death of the smoker. These campaigns stress the power that people have in preventing lung cancer, heart disease, and other risk factors associated with smoking. Thus, this and many other anti-smoking campaigns stress the fear and death associated with cancer, whereas social marketers who organize AIDS campaigns try to reduce the fears, and stigmas associated with AIDS and explain to their target audience how they can reduce the likelihood of infection. This idea of fear and death is extremely important in the marketing of AIDS. Fear was immediately associated with AIDS, and even before the term "AIDS" existed, fear actually prevented many people from addressing the disease within their communities. This fear also pushed them into denial about their own risk-taking behaviors. Today, social marketing campaigns must deemphasize the fears associated with AIDS.

HIV as an illness cannot be bought or sold; the fear surrounding HIV, however, can be. Consequently, a "profitable" market was formed to address the experience of being free from the fears associated with AIDS which include fear of transmissions, deaths, people living with AIDS, etc. These fears have become valuable commodities, or what Marx described as, "an object outside us, a thing that by its properties satisfies human wants of some sort or another" (1978/1867: 303). Thus, the disease itself is not a product, but there are countless products associated with AIDS, and as a result, this disease and especially the fear surrounding it have become valuable commodities with both monetary and social values. Social marketers are using the fear that people have in order to promote a freedom from fear. In fact, it is not so much the fear of AIDS as it is the 'peace of mind experience' of not worrying about death that is being marketed. This

peace of mind is sold along with the condoms, dental dams, finger cots, latex gloves, syringes, bleach kits, baby formula, and even knowledge about Cesarean Sections, abstinence, and especially prescription drugs to slow the progression of HIV.

"AIDS Awareness" has become a multi-billon dollar a year industry. For the past 20 years, countless sums of money have been poured into AIDS prevention and research all over the world. As the prescription drug companies can attest, billions of dollars can be made off of the fear associated with AIDS. For example, researching a cure or ways to further slow the progression of HIV, through medical studies and even behavioral and psychosocial studies, can cost a lot of money. There are untold numbers of AIDS service organizations, foundations, research institutes, and government agencies working to curb the spread of HIV and help those living with AIDS live a longer life.

Though devastating to most, the AIDS industry has provided jobs and opportunities for many whose voices may not previously have been heard. For example, organizations such as GMHC, San Francisco AIDS Foundation (SFAF), and Church Avenue Merchants Block Association (CAMBA) in Brooklyn, hire clients and community members as AIDS educators; GMHC even employs gay youth to create social marketing campaigns aimed at its target population. In fact, many other organizations, especially gay social service centers, such as People of Color in Crisis (POCC) and gay community centers from Los Angeles to New York, receive a majority of their funding from government agencies and foundations based on their AIDS prevention and educational services. Case in point, in 2004, The Balm in Gilead reported receiving $3,365,103 on its IRS income tax, with three and a quarter million coming from government grants alone. Other organizations such as The Black Leadership

Commission on AIDS (BLCA) reported $1,280,243 and GMHC reported having received $20,158,172. Interestingly, over half of the funding from GMHC ($10,883,666) come from both direct and indirect public support, but all of the funding for BLCA come from the federal government. On a personal note, for three years I received an ASA fellowship provided by monies from a NIMH grant based on my aspiration to do "AIDS research.[65]"

Organizations such as The Balm in Gilead continue because there is still money in AIDS (although these funds have been decreasing), as well as the commodified fear associated with AIDS. Yet, AIDS is not worth the same to everyone. In exchange for peace of mind, health, even life, AIDS knowledge and facts are produced and reproduced to sell the experience of feeling free of fear. Different communities have constructed this freedom from fear in different ways, and this "fear-free AIDS" is being addressed within social marketing campaigns. The Balm is marketing its reframed version of AIDS – a stigma-free, fear-free version – and is using the Black Church as its vehicle to reach its target audience, the Black community.

For 20 years now, AIDS knowledge, facts, awareness, and prevention have been bought and sold as a product, and the nature of this product depends on the audience and

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[65] Interestingly, the race-based organizations described above, BLCA and The Balm in Gilead, have received either a small fraction of their funding from individual support or none at all. Most of the funding for these two organizations come from governmental support, whereas GMHC, though it has a substantial number of people of color in its clientele (it even has a Black female executive director) has received over half of its funding from individual and foundational contributions. Since Bush has been in office, government funds have decreased for sexuality-based programs, which could have had an impact on the government funding of GMHC. In addition, I would imagine that GMHC receives much, if not most, of these funds from gay and lesbian contributors and organizations. This leaves me to wonder why government funding is so high with race-based organizations, yet their private support is low to non-existent and why the opposite is the case with gay organizations. This probably has a lot to do with many Blacks not having the excess income to contribute to these organizations.

the marketers. I argue that the exchange value of different versions of reframed AIDS knowledge changes depending on the group's perception of the AIDS identity. For example, Black gay men in the ball community will not place the same value on AIDS knowledge that has been reframed for the Black Church. And the exchange rates are not as high for housewives in the Midwest as they are for gay men of color in New York and Los Angeles. Thus, depending on the group, the social construction of an ascribed AIDS identity[66] and the fears associated with this identity have been marketed and sold in different ways, and each of these different campaigns have used different strategies. As a result, The Balm in Gilead has been able to exist because The Balm is paid to take the Black Church's perception of the AIDS identity and market its reproduced, church-appropriate AIDS information back to the Church, addressing its fear of AIDS.

The Balm in Gilead Sells AIDS:

According to Seymour H. Fine's book on *Social Marketing*, one of the first steps in developing a successful social marketing plan is to know, "the potential *purchasers* in this particular market and what needs and wants these people have" (1990: 5), and then to see a clear need for the product. The Balm in Gilead goes to great lengths to take away the fear and the stigmas associated with AIDS that have prevented many church leaders and congregants from addressing HIV/AIDS. In the case of The Balm, the potential purchaser is the Black Church. The Balm must know, as Seymour (1990) suggests, the "audience, target market, market segment, constituency, customers, and clientele" (6), and must know the best ways to reach out to them and what appeals to them. By properly

[66] As described in Chapter Four, an ascribed AIDS identity is an identity placed on individuals believed to have AIDS.

utilizing this knowledge, The Balm can appropriately sell the need for successful HIV/AIDS promotion, and thereby, the product.

"Knowing" the Audience and Their Needs:

Ogden, et al. (1996), authors of *The Prevention Marketing Initiative: Applying Prevention Marketing* (1996), stress that an understanding of "the audience" (8), is of the utmost importance in any social marketing campaign. This knowledge has special relevance for social marketers who address HIV/AIDS. Ogden et al. (1996), point out that social marketing campaigns directed at AIDS prevention are particularly trying, for "perhaps more than any health challenge of the last several decades, preventing infection with HIV and other STDs requires an understanding of some of the most complex and intimate human behaviors." (8). They (1996) go on to note that, as a result, social marketers place, "tremendous emphasis on knowing as much as possible about targeted audiences and their behaviors and what determines those behaviors" (8). Since The Balm in Gilead works to have a better understanding of what AIDS means to the Black Church – the Black Church's social construction of AIDS, or its AIDS identity – it develops or reframes AIDS related knowledge to address its needs and concerns. Ultimately, however, the target audience for The Balm in Gilead is not just the Black Church, but the larger Black community.

When I first met with Pernessa Seele in November 2004, she told me that in order to reach the Black Church, you have to "know" the Black Church. In fact, she repeated this to me several times during my tenure at The Balm. During our interview, Seele noted:

> I think the ideal process of knowing the Black Church is having grown up in the Black Church, having a history and legacy of the Black Church, having been

> connected with the generation of folk who have been in the Black Church, so that I know the Church from my perspective today. But I also have the values of having been with my grandmamma in church, having been with my mama in church, having been with my aunts and uncles and my grandpapa in church. So knowing the Black Church, knowing its history, knowing what it has been for Black folks for generations informs me on what the Black Church is. (Seele)

Because of Seele's intimate understanding of the Black community, and the "behaviors" and "beliefs" (Ogden, et al. 1996) among many Blacks, Seele knows the role that the Church plays within the Black community, and she knows that the best way to reach the Black community was through the Black Church. Because most Black Churches did not address HIV/AIDS, Seele organized The Balm in Gilead as an organization to both address and understand the Black Church's perspective of the AIDS identity, as well as to reframe knowledge in accordance with its values and beliefs. As a result, although The Balm in Gilead is trying to reach the larger Black community through its social marketing campaigns, its immediate target audience is the Black Church. Thus, "knowing" the Black Church becomes a necessity.

There is no denying the power and influence of the Black Church; it is the most effective way to reach the Black community. The Black Church is where Blacks come together not only to worship but also to discuss social issues and concerns. Many Black Churches have provided school, housing, food, clothing, and even health care because as Dr. Moon-Howard contends, "taking care of the body is part of the spiritual growth of the individual" (Moon-Howard). Black Churches do this not only for their congregants but also for their larger communities. Pragmatically speaking, "you have an organized structure [within the Church] in which to distribute information… [and] the Church has influence" (Griffin). As addressed in great detail earlier in this dissertation, the Black Church is the "cornerstone of the Black community (Holmes)," and "all issues come to

the Black Church, and that's culture, that's years of culture and years of heritage, where everything comes into the Black Church" (Cheek). According to Seele, that is why she initially reached out to the Black Church. She states, "It is, historically, the only institution owned and operated by Black folks. There is no other institution that mobilizes the masses of Black people like the Church" (Seele). Latrice Wactor of Abyssinian Baptist Church believes, "if the Church had taken [on the virus] from the onset… I think [for] communities of color, the numbers would not be as high as they are now."

African Americans have the highest rates of HIV/AIDS in the United States, yet many Black churches have done nothing to curb the rates of HIV among their congregants and community. As a result, The Balm in Gilead has defined a clear need within the Black community for both the rates to decrease and for an increased capacity of faith institutions to address HIV/AIDS. One of the first steps is creating 'need arousal' because, according to Kotler and Andreasen (1996), "the consumer has to see that there is a need to pay attention to such information" (1996:120). This sort of catalytic action was demonstrated during the original march around Harlem Hospital, when Seele and a number of other religious leaders marched in their ceremonial garments around the hospital. They wanted to call attention to and demand acknowledgement from other faith leaders in the community of the patients dying of AIDS within the hospital walls. This need arousal "stimulated information seeking" (Kotler and Andreasen 1996: 120) and led to churches to inquire about the march, which turned into to an annual Harlem Week of Prayer for the Healing of AIDS, then to The Black Church Week of Prayer for the Healing of AIDS, and eventually to The Balm in Gilead.

Many churches were anxious for church-appropriate information about AIDS. Debra Levine explains:

> There were not messages geared toward houses of worship. We expected our senior[67] service to get it and to be able to take this information and absorb it and give it back to the community and it is like any other subpopulation, you have to design the curriculum. If you are working with women and you have to design the curriculum, you need the women's names. If you are trying to get a message out to women then you design the message specifically to a woman that you're targeting. House of worship were not targeted. They had no curriculum. They didn't have a language in there that talked about prayer and the importance of prayer, that didn't talk about ways that pastors could write sermons that wouldn't conflict with their doctrine. They had not space provided for senior service to sit down and do a peer to peer conversation about how do you manage this. And so I couldn't fault them for what they didn't have. Because again, you have applicants coming in, like from the Gay Men's Health Crisis, like with this very explicit literature, very explicit pictures, coming into houses of worship saying you have to give out condoms. You have to have this conversation, with no respect for the fact that this is an institution that has its own rules, its own regulations, its own cultural competency, its own language, and so pastors got very turned off because there was no [in between]. People would say, "it's either this way or no way."

Thus, a market developed for Black Church-specific AIDS information. The Balm in Gilead wants its target – the Black Church – to realize that it has a need to abide by its 'Christian duties' by addressing HIV within congregations. In addition, by associating AIDS with the Church, it removes some of the stigma associated with AIDS, thus easing the process of increasing awareness. One of the main techniques The Balm in Gilead uses to market its reframed AIDS information to these churches is to remind them of their Christian duty to help the sick and suffering.

The Balm in Gilead wants churches to organize AIDS ministries and address AIDS within their congregations, but it also recognizes the difficulty that many churches may have in addressing the taboo topics associated with AIDS, such as sex,

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[67] Senior is a term often used to describe older, influential people, sometimes clergy, within the church.

homosexuality, and drug use. In order to encourage churches to get past their beliefs about the behaviors associated with AIDS, The Balm in Gilead works to "increase the acceptability" of AIDS awareness within the Church, and it does so by focusing on the beliefs and values (Kotler and Roberto 1989: 24) found within Christianity.

The Balm uses the idea of "good Christians" to market AIDS. Good Christians have to abide by God's instructions to care for all, regardless of their ailment or their sin. The Balm in Gilead counts on and markets to the Black Church's sense of Christian duty and responsibility to help those suffering with AIDS, and to prevent others from becoming infected. There has been some difficulty in the past with addressing HIV because of the "sinful" behaviors and identities associated with the transmission of the virus. "When folks argue it's wrong to minister to 'the sinful,'" says one Balm handbook, "we may simply ask them: 'What would Jesus do?' It is in our power to follow His example and dismantle the stigma, shame, and blame attached to HIV/AIDS, moving instead to a place of unconditional love" (The Balm in Gilead 2003a: 13). Thus, in order to market its church-appropriate, fear-free version of AIDS, The Balm had to understand and emphasize the themes found within Christianity that would make having an AIDS ministry acceptable. It markets to the sense of duty inherent within Christianity that many churchgoers abide by, and this understanding is at the foundation of The Balm in Gilead's work.

Though a community-based organization, workers at The Balm also feel as if The Balm is a religious organization that operates in accordance with Christian values. Rev. Mugarura of The Balm in Gilead believes: "Our mission is to reach out to people in need. I would recall them, you know… the outcasts, those vulnerable children and widows and

infected people…so because of our mission, the mission of the Church, which is to reach out to the people, it helps us. It helps in shaping the program we have to do… It is an obligation, something you must do as a mandate from God." Thus, knowing its target audience, The Balm understands the obligations that churches have to help those who are suffering and sick, and The Balm works to emphasize these obligations in its publications and teach other ministry leaders how to encourage this feeling of obligation within its ministries.

The Balm frames AIDS in a way that accords to the teachings of the Church, and uses Christian duty and obligation as a way to open dialogue and encourage churches to confront the AIDS epidemic within their congregations and communities. For example, alluding to Christian obligations, Pastor Davis states: "Jesus once said… when I was sick, you visited Me, when I was naked, you clothed Me, hungry, you fed Me. In prison, you visited Me… He said if you had done the least of these to the least of My children, you've done it unto Me… Well, I never believed in dancing to the tune of a drummer, but I sure believe in walking in the footsteps of Christ" (O. Davis). The Balm frames AIDS education and awareness in such a way that it becomes the duty of any true Christian to address AIDS, even if it means working with perceived "sinners," because as Pastor Davis contends, it is a sin not to help out your fellow man. He explains:

> I'm going to do what I know and have studied—the Bible, to be the truth, as taught and that means there's no exceptions to whom you give your loving charity to help… if I've got two coats and someone is naked, I am guilty if I don't give that one coat away. That's a naked person! I don't care if they are a crack head, a big mack crack attack wallowing in the gutter! If he is naked in front of the door and I have two coats, I must, if I am a son, a disciple of Christ, give that person a coat! He is naked! He is freezing!" (O. Davis)

Understanding the Black Church and the notions of love, acceptance, and obligation has helped The Balm work with the Church to confront the stigmas associated with AIDS and their 'uneasiness' that follows with addressing AIDS. Even though churches may not approve of the behaviors associated with HIV transmission, The Balm emphasizes that it is the Christian duty of the Church is to prevent the spread of the disease. This emphasis reassures churches that addressing AIDS does not mean that they have to condone the behaviors associated with HIV transmission. The Balm stresses that, in fact, churches are well within their Christian duty to address HIV. With this in mind, The Balm has reframed AIDS facts so as to make AIDS an acceptable discussion within the Black Church. During my interviews and analysis of the content, I identified five major themes that arose in which The Balm emphasizes Christian obligations to encourage churches to address AIDS: prayer, forgiveness, love, acceptance, and the responsibility to care for others.

Prayer:

One of The Balm's messages, "Pray for the Healing of AIDS" appears on many Balm products and is its "slogan." According to Kotler and Roberto (1989) this is a "one-sided [message, and these messages] appear to work best with people who are already favorably predisposed to an idea or practice" (196). The Balm recognizes that AIDS may be difficult for churches to address, but all churches can at least pray for those suffering from AIDS. Prayer is a common denominator among all churches and no matter how one may feel about those living with AIDS, they can at least pray for them. Darlene Cheek notes that the idea to focus on prayer was a:

> step by step process because at no point did we ever say all we want to do is talk about it. I mean it started out with prayer because that's one universal thing that

> every Black Church is going to do. Every Black Church is going to pray. So if we can first get you to say it in a prayer, it starts to open up the conversation. You can then start to have a conversation. If I first can say in a prayer "God Bless those people with HIV and AIDS," then it opens a door – even if it's a crack – it opens a door for you to be able to go in and say this disease is 100% preventable and talk about abstinence and talk about prevention methods, and talk about other avenues that the Church then becomes ore open for the families that are dealing and have dealt with the disease. (Cheek)

Through its workshops, teachings, and especially its publications, The Balm emphasizes the roles that churchgoers have as instruments of God.

The Balm publications, *The Black Church HIV/AIDS Care Handbook* and *Blessed are They That Comfort*, are saturated with Biblical quotes and phrases reminding churchgoers of their duty as followers of the Lord. Seele and The Balm in Gilead also recognize these themes and focus on them in its publications. One Balm publication notes: "It is wise to talk about AIDS in terms of scripture. For as Jesus ministered to the sick and outcast so much, we offer unconditional love, acceptance and service to our brothers and sisters who suffer" (The Balm in Gilead 2003a: 13).

The Balm also encourages other churches to use the Bible as justification for an AIDS ministry. Rev. Claudette Davis, the head of the AIDS ministry at St. Timothy Baptist Church and a longtime Balm volunteer contends, "I bring my message [about AIDS] to them from the Bible, and there are places where you can find references that you can use, and it is all a matter of choice of words and emphasis on certain situations" (C. Davis). The Balm understands this sense of obligation and responsibility, and it expresses this sentiment in 2001's *Extending Grace! An AIDS Ministry Handbook*, where tips are provided on developing a ministry. It states, "It's important to help church members grasp the Christian obligation the [C]hurch has to provide an AIDS ministry" (The Balm in Gilead 2001: 8). The following section examines this sense of Christian

duty and its underlying themes of responsibility, love, acceptance and forgiveness as applied to the fight against AIDS by The Balm and those who organize AIDS ministries.

Responsibility to Care for Others:

Angela Griffin of Berean Baptist Church believes that having an AIDS ministry is:

> just one of the responsibilities that you should have as a Christian. You should be about making sure that people have the best life they can have. Anything that interferes with that, whether it is the loss of their health or someone that they care about… then it is gonna impact their life, it's going to impact them as a person [Addressing AIDS] is part of our responsibility to do what we are supposed to do.

Darlene Cheek spoke about how sending out AIDS information, and telling Christians that helping to fight AIDS is part of their responsibility, is very effective in addressing HIV. She believes, "As Christians, [addressing HIV/AIDS] is part of our responsibility. Now when you start to talk to Christian people or religious people about responsibility, that kind of opens them up a little bit more to hearing you than if you just start spouting statistics… they hear nothing" (Cheek).

Even the name "The Balm in Gilead" markets to this sense of duty. Sullivan says, "I even love the name, The Balm in Gilead. There is a healing that needs to take place and there is something that is missing and a lot of it, I think, falls squarely on the shoulders of Christians, and we are not doing our job as a Christian" (Sullivan).

Recognizing that topics such as premarital sex, masturbation (as a preventative method), and prostitution may be difficult to address, The Balm points out that it is, "important that we separate our personal and theological beliefs regarding people's behavior from our Christian responsibility to address human suffering by educating people about AIDS" (The Balm in Gilead 2001: 9). The Balm encourages churches to

use quotes such as 1 John 3:18: "My children, let us not love in word or tongue, but in deed and in truth" (The Balm in Gilead 2003a: 13).

Love

Another theme is that of love, "You see, Christians are supposed to be loving" (O. Davis). Pastor Davis of Timothy Baptist Church in Brooklyn spoke extensively about the importance of love within Christianity. "It's all about love, really. Love thy neighbor as thy self. It didn't say pick and choose <laughing>… Jesus never picked and chose whom to love" (O. Davis). He explains, "God speaks love. And if you don't believe that the power of love is the greatest power going, that the power of love can change the hearts of men, then you really don't believe in God" (O. Davis).

For, regardless of the sin, one's Christian duty is to care for all. Pastor Davis elaborates by stating, "Jesus came for those he considered sinners – who the world called sinners – those who would not obey God's laws. Jesus did not stop because they were such and such, or they did so and so. He still brought his compassion to them. He didn't approve of it and he told them so, but he loved them just the same" (O. Davis). He goes on to state: "I'm going to do what I know and have studied in the Bible to be the truth, as taught, and that means there's no exceptions to whom you give your loving charity to help" (O. Davis). In its 2004 publication, *Blessed are They That Comfort*, The Balm quotes Romans 8:39, "Nothing shall be able to separate us from the love of God," asserting the eternal and forgiving nature of God's love.

Acceptance:

The Balm lists 12 things that churches can do to address AIDS in *Blessed are They That Comfort,* and the first is, "[w]elcome everyone regardless of their HIV status

or sexual orientation" (The Balm in Gilead 2004: 9). Because of the sin that is associated with AIDS, the idea of acceptance, especially acceptance of one's lifestyle is an important aspect of any AIDS ministry. Sullivan maintains, "People won't feel comfortable around you if they don't think that you can accept who they are, because if someone is sitting here and they think that you are passing judgment on them, they are not going to open up to you. In fact, what they are going to do is become defensive and remove themselves from you, and so how am I doing God's work by driving people out of the house of God?" Cheryl Sullivan of Emmanuel Baptist Church goes on to say: "You can't ostracize people. What the heck? You can't tell people who can and cannot love Christ" (Sullivan). Pastor Davis agrees; churches must minister to, "[w]hosoever will come. You know, if someone is in need, and we have, give it to them" (O. Davis).

In The Balm publication, "Blessed are They That Comfort: An Introduction to HIV/AIDS for Black Congregations," The Balm suggests that one of the things that a church can do is, "welcome everyone regardless of their HIV status or sexual orientation" (2004: 9). *The Black Church HIV/AIDS Care Handbook* cites Rev. Edwin Sanders of Metropolitan Interdenominational Church in Nashville as saying, "The truth of the Gospel is that we are all God's children… There is no immigration officer at the gates of Heaven saying who can and can't get in. Even in our weakness, we can still be made perfect. God's grace is available to us all" (The Balm in Gilead 2003a: 13). In focusing on this theme of acceptance, The Balm offers prayers, songs, and even responsive readings that can be used to remind Christians of acceptance: "We will see it and remember the everlasting covenant between God and every living creature of all flesh" (The Balm in Gilead 2003c: 13).

Forgiveness:

During World AIDS Day in 2005, I attended Timothy's AIDS Prayer Vigil. As congregants rose to tell of their experiences with AIDS and pray for those who were suffering, forgiveness was a constant theme. One woman stated, "Have mercy upon them Lord and give them forgiveness." In fact, the word "forgiven" was embroidered on a purple cloth draped over the podium from which Rev. Claudette Davis spoke. "That's the hardest thing in the world to do is this, forgive. That's the hardest thing for a Christian to do, forgive. But it requires us to see things as God sees them" (O. Davis). Pastor Davis explains, "Peter said 'Lord, how many times should I forgive my brother?' A lot of people get really ridiculous when he said four times or forty times, they believe that's it. Jesus was using a large enough figure just to say, forgive – as many times as it is necessary to forgive" (O. Davis).

Forgiveness not only helps those who have HIV, but it also helps in organizing a ministry not to blame people for their illness. "We have a habit of saying, I forgive but I ain't gonna forget. Now that's not forgiveness. I would think that a person who caught AIDS is really beating themselves in the head because of the fact that they have shortened their life. I think that's enough punishment. They don't need me or anybody else to come running up and saying, you're evil, you are sinful, you are gonna die!" (O. Davis). The 2004 publication, *Blessed are They that Comfort,* cites Luke 9:56, "For the Son of God is not come to destroy men's lives, but to save them," emphasizing that the role of the Church is not to punish or scorn, but to forgive.

While responsibility, love, acceptance, and forgiveness are the major themes that The Balm recognizes which are inherent within Christianity, ultimately The Balm

encourages us to, "remember the question: What Would Jesus Do? Jesus did not judge people; He interacted with the disenfranchised; He ate at the home of a leper cast-off from society; He healed the sick, gave sight to the blind and raised the dead. Jesus set the example that we should all follow—especially as we approach this epidemic" (The Balm in Gilead 2001: 10). The Balm in Gilead uses "certain verses from the Bible to support loving each other and messages that are anti-stigma against those who already have HIV and AIDS" (Perry).

Many of the Biblical quotes found in these publications refer to tales found in the New Testament, that emphasize the love and acceptance of Jesus and the charge that Christians should have to follow in His footsteps. Other phrases found in *Blessed are They that Comfort* (2004) include a tale where John explains how illnesses are not a result of sin or misdeed. In this story, the Apostles come upon a man who is blind and ask Jesus what sin this man or his parents committed to make him blind, suggesting that he did something to cause his own blindness, a perception similar to that commonly held about AIDS. Jesus responds that the man did not sin, nor his parents; he is just blind, and he is still worthy of helping. The Balm quotes the following: "Neither hath this man sinned, nor his parents: but that the works of God should be made manifest in him-John 9:3." During interviews, pastors and ministry leaders alike referenced the Bible as a guide on how to conduct oneself. Pastor Davis quotes Matthew 25:40, "Inasmuch as ye have done it unto one of the least of these… ye have done it unto me-" a scripture which is also found in The Balm's *Blessed are They that Comfort* publication.

However, the Christian duty of the Black Church in addressing AIDS is not its only level of duty. The Balm in Gilead reminds the Church of its status as the most

influential organization within the Black community and calls upon its sense of civic responsibility as a means through which to influence the Church to address HIV/AIDS:

> The Black Church is our community's most trusted and longstanding institution. It is the place Black people have always gone for comfort, healing and fellowship. The Church is our rock and our strength. It is where the civil rights movement was organized and from where Black leaders continue to arise. So it is altogether fitting that the Church should wage the battle against HIV/AIDS – our people's newest and deadliest foe. From Black pulpits and parishes across the land, let the message go forth… (The Balm in Gilead 2003a: 9)

Working with these themes of responsibility, love, acceptance, and forgiveness, The Balm in Gilead creates campaigns that will effectively market AIDS awareness and convince churches to develop ministries. By using these themes, The Balm framed AIDS as a social problem for the Black Church.

Reaching the Audience:

The Balm in Gilead markets its version of AIDS to the Black Church through a number of different mediums and campaigns, the most important one being The Black Church Week of Prayer (BCWOP). Described in great detail in previous chapters, and alluded to previously in this one, the BCWOP is the flagship campaign of The Balm, which began as a march around Harlem Hospital. The late Canon Williams, former rector of the Church of the Intercession in Harlem and founder and chairman of the board at Harlem Congregations of Community Improvement, remembers the event:

> Oh well, first of all you got to remember that she had, I mean she had some big names down there, I mean I was there, Wyatt Walker was there, Ollie Welsh was there, Bishop Quick was there, she had some other folk. Secondly, this is on the tail end now of the Civil Rights movement. All of us were involved in civil rights. Got to remember, Dr. Walker was Martin King, Dr. King's chief of staff. So seeing us march for some reason was, you know, it wasn't unusual, but they were marching for some cause—it had to be something right, because it was the right people marching. Preachers in their robes marching was not unusual, we

> often did that… we built on the civil rights march. What was unusual, it was cold as hell [laughing]. And here we were out here trying to sing these songs, and you know in the middle of the weather, and stopping to pray every now and then, well, wasn't unusual in Harlem! Preachers act crazy all the time. But it also resonated with both the staff and the people on the street, because it was clear what we were trying to do, we were surrounding Harlem Hospital with a wall of prayer. So we had tapped in to a preexisting understanding of the role of religion and health in the Black community. So, it was a natural. And what was unusual about it is that we were, we were doing it because there was presence in the community something that we did not all understand, but if anybody understood it God understood it.

So, when Seele began The Balm in Gilead, she had the support and backing of many religious leaders around Harlem, including Ethiopian Jews, the Yoruba, and Muslim leaders. Her model is that she, "first create[s] the awareness and [moves] organizations and communities, religious leaders through a model of stages of change, if you will, from being aware that something's an issue through to actually helping to provide technical assistance to leadership of religious organizations, to sitting at the table with policy makers" (Moon-Howard). Thus, in the early days of The Balm, the focus was on religious institutions in and around Harlem, not just the Black Church. Dr. Moon-Howard states, "It was really eclectic, and it was quite beautiful to see a prayer taking place around the healing of AIDS from so many different religious persuasions… There is an acknowledgement that African Americans and Black people are a spiritual people in general and have different and a very diverse range of religious organizations in which they participate."

Seele recognized the influence that community leaders have in promoting AIDS awareness and taking the stigma away from AIDS. The fact that well-known religious leaders and Black celebrities were willing to address HIV proved to many the importance of AIDS. Darlene Cheek describes an event in 1994 in which:

> Seele and The Balm in Gilead gathered together a group of religious leaders from all across the country to the White House for a three day conference [where they developed the African-American Clergy's Declaration of War on HIV/AIDS] and they all signed it. That was monumental because churches got to get this declaration in their hand and say, 'well, this is wonderful because so and so signed it, and he's a big person in the AME Church, or so and so signed it, and he's a big person in the Church of God in Christ. Or this is a very well known pastor here, that became very notable for them to say, 'well, you see pastor, this person is involved with this situation, so it's not like we are talking out of our head,' they can actually physically see if someone that they are familiar with and can relate to being supportive of this issue. (Cheek)

"The African American Clergy's Declaration of War on HIV/AIDS" describes a number of affirmations and duties that these clergy will hereby agree to, and a brief excerpt states:

> We, members of the clergy of African American churches in America, recognizing that as long as one human being remains uneducated, as long as one human being suffers from AIDS, it is one too many; we vow to develop comprehensive AIDS prevention programs for your youth; to develop effective AIDS awareness and prevention strategies for and with our congregations and communities; to provide supportive counseling to Persons Living with AIDS and to the their non-infected families and loved ones; and to preach consciousness-raising sermons about AIDS prevention and compassion for all, regardless of sexual orientation, drug dependency, or lifestyle choices. (The Balm in Gilead, 1994)

Well-known clergy and religious leaders such as Rev. Dr. Barbara L. King, Rev. Canon Frederick Williams, and Rev. Dr. Jeremiah A. Wright signed this proclamation. Seele often calls on well-known clergy for Balm sponsored events and campaigns. For example, the National Spokespersons of the 2006 Black Church Week of Prayer are, according to Seele, the leaders of the original "seven historical Black Church denominations as well as the leaders of six other national denominations and caucuses[68]."

[68] These spokespersons include: Bishop Gregory G.M. Ingram, the President, Council of Bishops of the African Methodist Episcopal Church; Bishop George W.C. Walker, Senior Bishop of the African Methodist Episcopal Zion Church; Bishop Marshall Gilmore, Senior Bishop of the Christian Methodist Episcopal Church; Reverend Stephen John

(The Balm in Gilead 2006: 2) including Bishop Carl Bean, the Archbishop of the first Black gay denomination, Unity Fellowship Church. These spokespeople fit rather well with the theme of the most recent Black Church Week of Prayer campaign, "United We Stand Against HIV/AIDS." Teresa Holmes describes how Seele plans and executes her campaigns in advance:

> [Seele] normally comes up and decides what she's trying to achieve this particular year. What market she is going after? What demographic group she is going after? So she makes that decision; then we could focus on who our spokespeople will be after that. Are we going for younger people? One year we went for the younger group and we had Mary, Mary, we had Bobby Jones, well, we mostly have him every year. He's a legendary gospel singer and he always brings in those traditional church folk because he is just the face for gospel. (Holmes)

The Balm in Gilead has gotten the support of Black Church leaders, political figures and celebrities, such as Rev. Al Sharpton, Bishop T.D. Jakes, Whoopi Goldberg, Cornell West, Elton John, Oprah Winfrey, the late Ossie Davis, and even President George W. Bush. These people have provided everything from monetary contributions and publicity to making speeches or performing at Balm sponsored events. The Church, community, and political leaders have come forward to help The Balm market its 'free-from-fear' AIDS campaigns, and the celebrity voices convey the urgency of AIDS and the impact it is having on the Black community. Additionally, during our interview, Teresa Holmes pointed out that in 2005, "The Balm in Gilead announced a partnership

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Thurston, President of the National Baptist Convention of American; Dr. William J. Shaw, President of the National Baptist Convention, USA; Reverend Dr. Major Lewis Jemison, President of the Progressive National Baptist Convention; Reverend Dr. Arlee Griffin, President of the American Baptist Churches, USA; The Reverend Canon Nelson Pinder, President of the Union of Black Episcopalians of The Episcopal Church; Dr. Dory Lingo, the immediate past President of the United Black Christians of the United Church of Christ; Bishop Melvin G. Talbert, President of the Black Methodist for Church Renewal of the United Methodist Church; Bishop Carl Bean, Archbishop of Unity Fellowship Christ Church.

with the CME, AME, and AME Zions, which were these women's missionary societies… [to] help address health disparities among Black people[69]."

Yet, The Balm in Gilead did not just focus on leaders within the U.S. Black community and well-known Black leaders within the Church. The Balm also focuses on leaders within individual Black Churches. Darlene Cheek contends, "We brought in leaders on how to talk in churches, how to go in and to organize churches in their community." The Balm trained these leaders to go in and address HIV within their own churches, helping to gain further support for HIV/AIDS within the Church. These individual church leaders address AIDS in ways in which they feel comfortable. By meeting churches "where they're at" (Seele), The Balm in Gilead, like many other service organizations, such as GMHC, HCCI, and the Brooklyn-based non-profit CAMBA, uses a harm reduction approach to addressing AIDS. Geneva Musgrave, a caseworker at CAMBA and a steering committee member of Emmanuel Baptist Church's Healing Touch Ministry described how she works to meet Pastor Trufant "where he's at" and works within the parameters of the Church in terms of AIDS education within the Church. When told that she was not allowed to distribute condoms within the Church Musgrave states:

> I kind of understood it at that point and I respected it, and said 'well, we are in here, let's do what we can do with what we have, and with respect of everyone as a whole, and we have the pastor's support, the senior pastor's support, so that was really important at that point, so the condom thing didn't matter, because I said, 'I know ways of getting around it.' If someone came to me and said, 'where can I get some from?' I would tell them if you meet me on the corner down the street, I will make sure I will have some for you. I won't disrespect this house, but if it is about saving someone's life because they are not there yet, then I will do that, but

[69] As part of this partnership, The Balm will work with these missionary societies to establish health offices within the district churches within these denominations to address HIV/AIDS.

> I won't do it here. But I won't do it on the corner… this corner is a public street, you know. (Musgrave)

Most often, to reach the Church, you must reach the pastor, because as Darlene Cheek notes, "in the Black Church, if the pastor doesn't approve it, it doesn't really fly." You must not just have an understanding of how the Church operates or how the congregation views HIV/AIDS, but also what, and as important, who can reach the pastor. Cheek explains, "We knew our challenges were trying to get to the pastors, and you found a way to do it by any means necessary. So if the pastor's aid club has the pastor's ear, things go to the pastor's aid club. If the nurses' unit has the pastor's ear, then you go into the nurse's club."

Much of the success of The Balm's work, and the work of other ministry leaders, comes from its ability to meet churches where they are. This is a key theme within social marketing. The ability to produce and market material based on the beliefs, perceptions, and especially from the point of view of the target community serves to better convince the Church to address HIV within its congregations and communities. One of the ways in which The Balm works to market its reframed AIDS knowledge is by using the media to gain as much visibility as possible.

Visibility:

Social marketing literature states that after an audience is selected, and material created, a means by which to distribute this information must be obtained (Kotler and Roberto 1989). The main way to market products, ideas, and even behaviors is through the media. Television and radio spots, as well as informative banners, websites, and newspapers, all serve to publicize not only The Balm in Gilead, but also to spread its

version of AIDS; and a lot of work goes into publicizing these campaigns. Teresa Lyles Holmes, a media consultant with The Balm states:

> Well, the purpose of the media relations campaign specifically for the Week of Prayer, is to solicit churches to participate in the Week. So it is very important that you start the campaign months out. Churches will get on board and get involved and get a plan together on what they are doing. So the purpose of the media relations or the goal for the Week of Prayer for the Healing of AIDS is to mobilize churches and to get their support and participation. So for that particular campaign it is very important and that's the same as with Our Church Lights the Way[70], which is in June, which is our HIV testing campaign. So [for] those particular campaigns it is very important to get the information out and to get your campaign going and your public awareness of it months in advance, which would entail getting it on the website, doing some type of mailing or general market press release out to try to [say] "Balm in Gilead is announcing its 17th Annual Week of Prayer in March of 2005." The churches will read about it and the ministers will read about it and they will be like, "ok, I want to do something for the Week of Prayer this year," so that's the whole purpose of that.

According to Holmes, when The Balm has campaigns, first:

> I develop media relations plans that consists of what I want to accomplish, who my target audience is. Who [are] the target outlets? I develop a press release, a media list. I then write the press release and give the press release to either those national or local outlets depending upon what my goal is and then follow up to secure media in nationally, or locally, or globally on whatever project or program that we are trying to bring attention to at that time.

This is a far cry from the original publicity The Balm sought when it was first organized. The Balm's target audience was always Black religious institutions; in the late 1980s and early 1990s, however, it was difficult for Seele and her early staff of three to reach out to those churches and community leaders and view "target adopters as individuals" (Kotler and Roberto 1989). Initially:

> You'd send out information and it'd say 'AIDS,' and [the churches] would either call you up and say 'don't send me this again,' or they would call you up and say 'what is this about.' And then the option is, you either, I mean the people that said 'don't call me with this,' 'don't send this again,' 'this is blasphemous,' whatever, whatever, you try to explain what it is, and then if they don't want to

[70] Our Church Lights the Way is The Balm's HIV/AIDS testing campaign.

> hear it, you say, 'Ok, fine. That's it.' And you hope that they will broaden their horizons. Sometimes that didn't happen. Sometimes they didn't want to hear it. (Cheek)

Currently, The Balm relies heavily on newspaper articles and television spots for publicity and visibility. Most of this media coverage is based on the BCWOP and the press releases sent to media outlets across the U.S. Teresa Holmes contends that this type of publicity:

> is very important for The Balm [for] two great reasons. The first reason: in the Black market, in the Black press, it is important for African Americas to see that you have an organization such as The Balm in Gilead that's working with Black Churches to empower them, to teach them how to educate their community. Because believe it or not, they need to understand that, how important these statistics are and how high they are and what risk we have in the African American community. We can't rely on general market media to tell us that. So it is very important that we get our message continuously told through the Black market, through the Black media. In the general market media, we appear more so as a more credible organization when we are covered by the general market media. So unfortunately, that's the way it's looked upon. When you see us in the Daily's, when you see us on CNN, national, international news, you see us doing quality work. It helps us get recognition, you get recognized by very powerful and influential people who are in control of dollars and cents at their philanthropic organizations and so that's why it's important to definitely get publicity.

These media campaigns that The Balm produces provide two functions: 1. to help educate the Black community about AIDS and 2. to provide publicity about The Balm as an organization. Teresa Holmes explains: "First of all… as we get the word out about… as we educate our community on this epidemic, we are letting people know, hey, you got an organization that is addressing this epidemic." Thus, these media campaigns have helped to not only advance the work of The Balm by advertising itself as reliable, but also these campaigns advertise and create awareness of AIDS in the Black community. The Balm's mere existence suggests that the Black Church can and should address HIV.

In addition, the publicity surrounding the BCWOP and other Balm events helps the Church to realize that:

> our constant presence, and our constant information giving and sending, our constant having different vehicles for people, and venues that people could relate to, our constantly being there, they can pick up the phone and call The Balm in Gilead and get someone to at least listen to whatever… We consistently stayed in the community, consistently stayed out there, our name was consistently put out there. (Cheek)

The Balm does not just publicize the BCWOP or Balm events, but it also helps the Black Church to publicize its events and use the media to reach a larger community.

For many Black churches, their ministry is just the first step, because ultimately their goal is to reach the larger Black community. Pastor Trufant explains, "I don't do ministry with an eye solely on the members of our congregation. I do ministry with an eye on our congregation and an eye on the larger community… I think that one, the issue is, becoming far more adept at seeing that this is a phenomenon that has to be fought on two fronts." In the training that The Balm provides for the Black Church Week of Prayer, a section is reserved for explaining to churches how to publicize the church's BCWOP events. *The Black Church Week of Prayer for the Healing of AIDS 2003 Training Manual* states: "Obtaining media coverage for the Black Church Week of Prayer for the Healing of AIDS is extremely important. In addition to encouraging people to come to your programs, publicity spreads the word and motivates more churches to address HIV/AIDS" (The Balm in Gilead 2003b: 1). This publication offers advice on developing press kits, selecting spokespersons, media lists, and even what types of photographs to take.

This type of publicity serves three functions. The first function is to publicize the church, and the fact that the church has an AIDS ministry. The second function of this

publicity is to educate people about AIDS and remind people that AIDS is still an issue that is plaguing the Black community. The third function is that it also advertises The Balm in Gilead, and its reframed AIDS knowledge which says that AIDS is a topic for churches to address. The Balm teaches these churches to utilize social marketing within their own congregations to suit best the needs of the individual churches. And the information that The Balm gives them also provides some guidance in how they might promote their own non-Balm events.

In *The 2003 Training Manual,* The Balm explains how to market best the BCWOP to churches and to individual congregations. This manual stresses: "The Black Church Week of Prayer for the Healing of AIDS can be customized to suit the specific needs and capacities of your church!" (The Balm in Gilead 2003b: 4). The only expectation of their participation is that they "1) incorporate HIV/AIDS prevention and compassionate care messages into the total worship experience of the first Sunday in March; and 2) host at least one HIV/AIDS educational program during the Black Church Week of Prayer for the Healing of AIDS" (The Balm in Gilead 2003b: 9). As discussed in the previous chapter, The Balm offers general advice for working with the Black Church, such as "respect the pastor and all members of the governing body and congregation of every church;" "always exemplify leadership in AIDS education;" and "find common ground and always operate within the circle," which goes back to the "meet churches where they are" discussion (The Balm in Gilead 2003b: 8).

In addition, a number of "Balm products" are sold in its online bookstore. These products include: large outdoor/indoor banners that advertise The Black Church Week of Prayer, BCWOP bulletins, bracelets that say "Pray for the Healing of AIDS," videos, and

even Balm publications such as *Blessed Are They That Comfort: An Introduction to HIV/AIDS for Black Congregations* and *Though I Stand At the Door and Knock: Discussions on the Black Church Struggle with Homosexuality*. These products not only just serve as educational tools but also to advertise The Balm and the various services this organization provides.

Social Marketing Drawbacks:

Although social marketing techniques can be an effective way of getting health messages across and have proven to be successful for The Balm in Gilead in reaching Black churches, they also have flaws. A number of ethical issues arise in the creation of social marketing campaigns, particularly campaigns with issues as sensitive as those brought up in relation to AIDS.

The third chapter addressed the moral panic that The Balm in Gilead created by re-defining AIDS as something that churches should face in order to encourage churches to concentrate on HIV and AIDS. The moral panic that was created, however, was not the "typical" moral panic in that religious institutions were the target, not the originators of the panic (Goode and Ben-Yehuda 1994a). As previously mentioned, these panics typically center on a deviant group that threatens to impact or infect another group. Goode and Ben-Yehuda provide examples of large-scale moral panics, such as the witch-hunts of medieval Europe, and discuss their aftermaths. In each instance of a moral panic, they believe there were, "explosions of fear and concern at a particular time and place about a specific perceived threat. In each case, a specific agent was widely felt to be responsible for the threat; in each case, a sober assessment of the evidence concerning

the nature of the supposed threat forces the observer to the conclusion that the fear and concern were, in all likelihood, exaggerated or misplaced" (1994a: 150).

I mentioned earlier that to encourage churches to see themselves and their community at risk for HIV/AIDS, The Balm in Gilead created a moral panic. I am not arguing that The Balm constructed those with AIDS to appear like "folk devils" and "deviants" (Goode and Ben-Yehuda: 1994a: 149). Nor do I believe that The Balm in Gilead utilizes "fear" tactics in its publications and manuals. The Balm publications that explain how AIDS is spread also make mention of the ways in which AIDS is *not* spread. For example, its *2003 Planning Guide* states:

> AIDS is not spread by:
>
> - Touching, kissing coughing, sneezing, tears or sweat.
> - Drinking from the same Communion Cup after an HIV-positive person.
> - Sharing the Baptismal Pool with an infected person.
> - Children playing together in Sunday school
> - Sharing cups, plates, forks or a meal with an HIV-positive person.
> - Touching toilet bowls or doorknobs used by a person with HIV.
> - Sitting next to a positive person in church or Sunday school. (2003c: 16)

The Balm's "Planning Guide" purposely makes mention of all the different possibilities of contact during a typical Sunday Service; as a result, these suggestions and the ways in which The Balm markets AIDS information are guided by the morality of the Black Church. Basil and Brown (2001) argue that the social marketing of AIDS prevention and awareness is not necessarily meant to cause panic, but to increase concern about AIDS. Chapter Five mentions the different AIDS statistics that The Balm cites from the CDC. Among these statistics are, "At least 100 people of color become infected with HIV in the United States each day… One in 50 Black men is infected with HIV (The Balm in Gilead: 2001: 5).

As previously addressed, The Balm is attempting to create a "panic of morality" among church leaders by suggesting that they are not living up to their moral obligations and standards to care for all those who are ill and suffering. To accomplish this, The Balm has to construct AIDS as the number one concern within the Black community, and they do so by utilizing social marketing techniques. I am not suggesting that The Balm is misusing social marketing techniques; on the contrary, I find its techniques to be non-manipulative, quite effective, and even necessary to encourage churches to address HIV/AIDS. Yet, I am suggesting that one can easily see where social marketing can be used to take advantage of a group, especially when the truths or the "facts" are contested.

Deborah Lupton (1997) writes that social marketing campaigns:

> are directed at creating docile citizens, who accept the truths of public health authorities without question. Evident in much health promotional literature on the use of the mass media are frank statements on how best to command audience members' attention, how to frighten them into acceptance of the message or persuade them to give up behaviors they currently enjoy. The primary goal is that of manipulation, often based on emotional appeals. (106)

For example, earlier in this chapter I explained how The Balm provides detailed instructions on how to utilize media outlets to publicize the Week of Prayer events. It is important to note that, unlike the typical social marketing campaigns that call for a change in behavior, The Balm's social marketing campaigns also call for a change in beliefs.

Another drawback to social marketing is that it can be used to "manipulate" (Fine 1990: 74) people into a particular behavior change, and in the case of The Balm in Gilead, manipulate church officials into addressing AIDS. In this regard, The Balm's social marketing techniques can be perceived as somewhat intrusive. Seymour Fine (1990) believes that one of the pitfalls of social marketing, and of marketing in general, is

that it can be intrusive – telling people what they should and should not be doing. Edgley and Brissett (1999) argue that this form of "meddling" has become an acceptable part of American culture, when done under the pretext of health promotion or religious beliefs. They contend that as a society, "we meddle in the name of almost everything: health, safety, efficiency, the bottom line, God, 'the children' – you name it, and there will most likely be someone there to meddle on its behalf" (Edgley and Brissett 1999: 2).

Meddling becomes much easier with the utilization of social marketing techniques. As mentioned above, the five themes that The Balm utilizes in encouraging churches to address AIDS are: prayer, love, forgiveness, responsibility to care for others, and acceptance. By using words such as "duty" and "required," The Balm – intentionally or not – removes the "free will" that churches have in choosing to address AIDS. In a way, they are shamed into addressing it. Seymour Fine argues that social marketers need to think of the "worthiness of the cause or idea" (1990: 74) in the manipulation of audiences by the use of these techniques, but I am sure that AIDS education and awareness are worthy causes.

Another drawback to The Balm's social marketing techniques is, in an attempt to be unbiased, The Balm in Gilead does not encourage churches to address what they do not want to address, but rather, lets them dictate what they feel comfortable hearing and addressing. This has particular relevancy to the debates surrounding abstinence versus safer sex. In an attempt not to turn churches off to hearing The Balm's messages, The Balm carefully selects information and fashions it in such as way as to make it acceptable for this audience. As such, the church-appropriate information they are marketing may not be most effective in preventing AIDS, but may simply be a selected form of

awareness, basically a sort of PG-13 version of AIDS, that churches are comfortable hearing. There should be an acknowledgement of what is not being addressed. Since The Balm in Gilead is producing AIDS information for the Black Church, there is the possibility that church officials may not only see themselves as susceptible to HIV infection, they may also not see themselves as welcoming to those infected with HIV. This idea that some church community members have of "they're not like me" (Basil and Brown 2001: 391) is very difficult to overcome.

Another social marketing drawback deals with specificity in campaigns. For just as AIDS information can be too general and not take into consideration the community specific issues that arise, it can also be too specific and exclude other groups. As I described above, The Balm tailors AIDS information for individual churches as well as the larger Black Church. Sometimes being too specific can exclude other groups, though. For example, this past September, The Los Angeles Gay and Lesbian Center created a new campaign. Plastered on billboards all over LA, particularly within gay communities like West Hollywood, was the campaign's slogan which simply read: "AIDS is a Gay Disease." The CEO of the Gay and Lesbian Center, Lori Jean argues that gay and bisexual men have forgotten about AIDS. Gay and bisexual men are disproportionately affected by HIV/AIDS in LA and she believes that this campaign will target these men and remind them about the disease (LA Gay and Lesbian Center 2006). Groups such as The Balm in Gilead as well as countless other AIDS service organizations all over the U.S. have fought against the notion that AIDS is gay disease for decades. In a way, this undoes the work these activists – both gay and straight – put into taking the "gay" out of AIDS.

Often in their zeal to encourage groups to participate in healthier behaviors, social marketers overlook the "truths" in their campaigns because many times there is an inherent assumption that the information being marketed is "correct" (Lupton 1997: 111). For example, the previous chapter discussed the incorrect, or exaggerated statistic among Black gay men, that 30% of Black gay men are HIV+. In the spring of 2006, I attended a workshop at Gay Men's Health Crisis which focused on GMHC's different social marketing campaigns. One campaign was, as the moderator called it, the 46% campaign. This campaign was based on a study conducted by the CDC which claimed, similar to the statistic cited by The Balm, 46% of Black gay men in the study were HIV+ and over 60% of them did not know it. GMHC volunteers and staff went around the Village to bars and clubs and videotaped people's reactions when they heard this statistic. However, there was no mention made of as the fact that this was part of a five city study conducted by the CDC; and, out of the Black men who were approached in bars and clubs, or otherwise where "MSM congregated" (CDC 2005a), in New York, Miami, Baltimore, San Francisco, and Los Angeles, and who chose to participate in this study, these men were HIV+. There was no mention made that the sample was not representative of the population of gay Blacks but was biased toward an overrepresentation of HIV+ men. They simply reported the statistic. I am sure this "shock tactic" (Lupton 1994: 53-55) was an effective approach. But, these "fear-invoking strategies" (Lupton 1997: 115) can reinforce negative stereotypes about Black male sexuality and promiscuity. As Lupton (1997) argues, stereotypes are rarely challenged when done under the guise of health promotion.

Conclusion:

Similar to other AIDS non-profit organizations, such as Gay Men's Health Crisis, The Balm in Gilead's function is to introduce AIDS as a social problem and provide audience specific AIDS education and services. However, The Balm is not simply providing information or "selling" a behavior or attitude change to an individual or a demographic, but to an institution. Unlike most non-profit organizations and other institutions that utilize social marketing techniques, The Balm in Gilead is unique in that its social marketing techniques are guided by religion and morality. Seele and others at The Balm in Gilead work to find the best, most appropriate ways to reframe AIDS information and facts to be church-appropriate. As a result, the creation and marketing of these AIDS materials are guided by the morality of the target audience – the Black Church. The Balm's AIDS materials are carefully framed to fit within a moral narrative whereby it seems that these churches are naturally receiving this material and that this material is not a deliberate creation by The Balm. Only by properly utilizing social marketing techniques will its messages be received and then applied.

In a fashion similar to mainstream marketing, social marketing devises ways to convince its target audience to adopt a particular behavior or attitude, or to purchase a particular product. Through social marketing techniques, groups and organizations learn to create and adopt information befitting their desired audience. That The Balm is educating churches about the AIDS epidemic and encouraging them to respond is a major departure from the typical AIDS awareness campaigns that tend to be moralistic and "appeal to people's anxiety and fear" (Lupton 1997: 115). Rather, The Balm takes a similar "moral" approach, but it does so with the Black Church as the target. By

understanding the Black Church's fear of AIDS, where this fear developed, and how this fear is manifested, as well as the Black Church's perceived AIDS identity, The Balm can adequately develop campaigns such as The Black Church Week of Prayer, to advertise its reframed AIDS knowledge to these Black Churches.

According to The Balm's 2003 BCWOP training manual, the BCWOP "works" as a social marketing campaign because it:

- is the largest AIDS awareness program targeting Black America;
- is a national AIDS awareness program to educate and mobilize African American religious communities to become centers for HIV prevention and treatment education and compassion;
- is a vehicle for spiritual renewal, transformation and HIV prevention education for every individual and church community taking part;
- is effective because African Americans regard prayer, education and social location in close proximity;
- helps to create social environments that are conducive to addressing HIV/AIDS issues and to supporting people and families affected by the epidemic;
- links Black Churches with AIDS service providers in their locales;
- results in conscious change within Black communities and is a catalyst for year-round church-based community AIDS education programs. (The Balm in Gilead 2003b: 3)

In the end, The Balm is working to sell a version of AIDS that is appropriate for the Black Church. There is no doubt that individual Black churches would have eventually addressed AIDS whether or not they had received help from The Balm. But The Balm has helped the Black Church, as a larger institution, address HIV/AIDS in a manner befitting its morals and values. The Balm has made it possible for churches to feel more comfortable addressing the complex issues associated with HIV transmission.

Accepting The Balm's reframed facts really depends on the openness or even the readiness of the church to accept the message of The Balm and address AIDS within the congregations and communities. The approach of "meeting churches where they're at" is

key to understanding the success and the work of The Balm in Gilead and to addressing HIV in ways that these individual churches find appropriate, encouraging them to listen. This approach does not just apply with AIDS and the Black Church, however, but also with any individual, group, or community.

I must note that The Balm in Gilead is not requiring churches to do anything beyond simply increasing levels of awareness within the Church. What the churches do with their newfound knowledge is up to them, and this tolerance is a key principle within social marketing. The best market campaigns encourage people to have options or reduce a behavior that is harmful for them; there is a higher likelihood for success that way. What is important is that Black churches are able to address HIV/AIDS on their own terms, ways that are helpful and respectful to their parishioners, and fit within the lines of what is acceptable for their faith community.

Chapter 7:

Tending to the Flock:

The Black Church AIDS Movement Continues… and This Dissertation Concludes

AIDS has taken a major toll on the Black community. As previously stated, Blacks have the highest rates of HIV/AIDS in the U.S. – and the world for that matter. One of the reasons attributed to these elevated rates was the hesitation on the part of Black religious leaders and institutions to take an early stand against the AIDS epidemic (Cohen 1999; Fullilove and Fullilove 1999; Weatherford and Weatherford 1999; Dalton 1989). This dissertation has documented the involvement of several New York City Black churches in the Black Church AIDS movement and how this was influenced by a community-based organization. The Black Church has taken an active role in addressing AIDS within the Black community, and this is due, in large part, to the work of The Balm in Gilead. Prior to The Balm, my research indicates that a number of Black churches believed that by addressing AIDS, they risked sending a message condoning the "behaviors" associated with HIV transmission. As this dissertation has shown, however, The Balm was able to construct AIDS as a social problem for the Black Church which, through time and effort, was then able to mobilize against the epidemic within Black communities.

In the first chapter I wrote that I had four major goals in writing this dissertation. My first goal was to better understand how social problems were constructed. Ultimately, I found that the Black Church did not mobilize early on against AIDS

because it was not constructed as a social problem for the Black Church. As a result, The Balm in Gilead created a moral panic (Goode and Ben-Yehuda 1994) among Black Churches. As described in the previous chapters, this panic resonated with Black religious leaders and congregants, thereby encouraging them to see the toll that AIDS was taking on the Black community and the role that they could play in AIDS education.

The second goal was to understand the social construction and reproduction of AIDS knowledge. Through my dissertation research, I found that The Balm in Gilead understands how the Black Church views AIDS, or what I refer to as the ascribed AIDS identity, and works to reframe AIDS in such a way that it resonates within the Black Church as a social problem.

My third goal was to give credit and draw attention to the Black churches and religious institutions that are addressing HIV/AIDS. So much emphasis has been placed on what the Black Church has not done that it is time we focused on the substantial work that is being done to curb the rates of HIV within the Black community.

The fourth and final goal of this dissertation was to contribute to the literature on the sociology of knowledge and the social constructions of health and illness. The ways in which AIDS was originally constructed delayed the response of Black religious leaders. Understanding the ways in which illness and disease are both socially and culturally constructed will not only benefit the larger study of sociology but also will provide information which can be directly applied to help communities and groups.

In this concluding chapter, I return to the many issues addressed within this dissertation. In particular, I will revisit some of the sociological theories addressed and discuss the theoretical contributions of this research. I will also provide a discussion of

policy concerns, which relate to funding, the complications of Faith-Based Initiatives, and public health initiatives. Finally, I highlight the ways in which New York City Black churches are participating in, and continuing, the Black Church AIDS movement.

Contributions:

As important as it is for me to study AIDS in the Black community and address issues that are very close to me, I am ultimately a sociologist, and contributing to this discipline is of the utmost importance to me and has helped to fuel my research. There are many different bodies of knowledge that I have pulled from in order to conduct this study – queer studies, race and ethnicity, gender studies, sociology of religion – but the main focuses were on social movement theory, the sociology of health and illness, social marketing, and the social construction of knowledge.

Social Movement Theory:

As detailed in the third chapter, in the late 1980s, most Black churches did not see AIDS as an issue for the Black community. According to my respondents, AIDS was a White gay disease, or a disease of sinners. As a result, many Blacks did not think that they were susceptible to HIV infection. The stigmas associated with AIDS and a lack of knowledge on the part of Black Church leaders and congregants prevented them from not only addressing AIDS within their own congregations, but also ministering to those dying from AIDS. Upset by this, Pernessa Seele organized the Harlem Week of Prayer and a march around Harlem Hospital by Harlem religious leaders. These events became the catalyst for what I describe as The Black Church AIDS movement and the creation of The Balm and Gilead, the organization founded to sustain this movement.

As noted by my respondents, The Balm in Gilead, and particularly Seele, understood the ways in which AIDS was viewed by Black Church leaders and congregants. They believed that The Balm and Seele not only knew why Black churches (and the larger Black community) were hesitant to address AIDS (see Chapter Four), but also what would resonate with Black churches so that they would address AIDS. Seele knew the role the Black Church played within the Black community and believed – as she still does today – that she would be able to reach the Black community by going through the Black Church. The tactics that she employed to encourage Black religious institutions to take up AIDS as a social cause is a prime example of the framing process and how this can create a social movement (Benford and Snow 2000; Babb 1996; Snow, et al 1986). Chapter Three also provided a discussion of health social movements (Brown and Zavestoski 2005; Kolker 2005) and how frames were used in constructing health issues as a "social problem" (Kolker 2005; Spector and Kitsuse 1987). The findings that I presented detailing the formation of The Balm in Gilead as a health social movement organization fit well within this body of literature. My research also greatly contributes to this literature by showing *how* culturally resonant frames are created under the constraints of a religious community, and how such frames are used to reach both the target audience and sustain the movement.

The Balm in Gilead was able to successfully create a social movement within the constraints of The Black Church. The Balm was unable simply to use culturally resonant frames (Kolker 2005) or focus on symbolic meanings (Swidler) in the creation of The Black Church AIDS movement but rather was constrained by the morals, values, and religious ideology of The Black Church. By utilizing understandings of prayer, Christian

obligations and duty, as well as an understanding of the role of the Black Church in the lives of African Americans, The Balm was able to package and even to "sell" AIDS. Though Futrell (2003) discusses framing constraints in relation to a movement's opponents, research does not examine religious ideology as a constraint in the framing of a health social movement.

My dissertation research is an example of my larger research interests, which concern how a social problem is framed (Spector and Kitsuse 1987) and how issues relating to health and health care can be framed based on themes and ideas that resonate with its target population (Kolker 2005). The idea of "framing a problem" has great relevance to many areas of sociology. This concept can be applied to addressing a number of social issues such as missing children (Best 1987), labor disputes (Babb 1996), and even understandings of White separatism (Berbrier 1998); furthermore, it holds great relevance to the development of health social movements. The problem of framing is especially important in the case of the Black Church whose congregants, as this dissertation has addressed, were not targeted by mainstream AIDS awareness campaigns. As I showed, the Black Church's ability to reframe AIDS opened up the possibility of reaching and affecting the lives of countless African Americans.

Theories on the Sociology of Health and Illness:

Just as social movements are framed, disease and illnesses have also been framed (Brown 1995; Rosenberg 1989) and constructed (Conrad 1997; Lorber 1997; Lupton 2000; Brown 1995). Chapter Four examines the social construction of health and illness, discussing the distinction between illness and disease as well as how illnesses are created based on time, location, and meanings (Freund and McGuire 1999; Conrad 1997; Lorber

1997; Brown 1995; Sontag 1989; Rosenberg 1989). The chapter also provides a discussion of medical anthropology and focuses on the influence of culture in the creation of a disease (Lupton 2000; Martin 1994; Herdt and Lindenbaum 1992; Treichler 1992; Kleinman 1988; Martin 1987; Kleinman 1980). As a result of the meanings and symbols associated with AIDS (Patton 1990; Sontag 1989), AIDS has been both stigmatized (Herek 1999; Herek and Glunt 1997; Herek and Glunt 1988) and culturally constructed based on its stigmas (Herdt and Lindenbaum 1992; Treichler 1992; Goldstein 1990).

In the mid-1950s, when the first academic programs exploring the sociology of medicine began to emerge, they capitalized on previous "collaborations[s] between physicians and sociologists". The field then expanded to include studies on the social institution of medicine, the social impact of illness, and later on the construction of illnesses and disease. In 1973, August B. Hollingshead wrote, "Medical sociology is in sore need of research on different approaches to health care prevalent in different cultures and societies" (Hollingshead 1973: 533, 540). My hope is that this dissertation contributes to the body of knowledge that addresses his thirty plus year old concern.

Understandings of cultural construction have particular relevance for AIDS in the Black Church because, as I argue, the Black Church has a very particular understanding of HIV/AIDS. Throughout my interviews, my respondents explained the unique views that the Black Church has on AIDS. These views have been informed by the experiences that the larger Black community has had with issues pertaining to sexuality, homosexuality, and drug use. Respondents believe that The Balm in Gilead has an understanding of the ways in which the Black Church has viewed AIDS. In the fourth chapter, I describe this "view" as the AIDS identity and define it as an ascribed identity

that is associated with HIV/AIDS, such as drug addict, homosexual, adulterer, sex worker, etc. Because The Balm understands the Black Church's view of the AIDS identity, what it means to the Black community, and from where it originated, they are able to reframe AIDS information to be audience specific.

The Black Church is not only a social institution, but a cultural institution (Glynn 2000). What makes the work of The Balm particularly interesting is that The Balm understands how AIDS is socially and culturally constructed both within the larger society and within the Black Church. As mentioned above, The Balm understands the norms and values of the Black Church as a cultural institution and is able to construct AIDS knowledge for the Black Church based on its understanding of AIDS and HIV transmission. The Balm is able to take constructed AIDS information and reframe it within the cultural context of the Black Church. Medical sociology does not place enough emphasis on the creation and construction of health related information within a more cultural context. Current discussions within the field may include how societal culture influences the creation of medicalized facts and information, but not necessarily how this same process can be used to address a health issue with a community.

Though quite similar, I make a distinction between the social construction of health and illness and the cultural construction of health and illness. There are studies within medical sociology that do focus on culture, such as Joan Jacobs Brumberg's (1997) essay on the cultural context of anorexia nervosa. Brumberg's essay, however, deals with anorexia within a large-scale cultural context, i.e. generational perspectives on anorexia, not the smaller, more localized cultural context for which I am arguing. Medical sociology can greatly benefit from further research on community and cultural

understandings of health and illness. It can also learn from medical anthropology how community and cultural norms dictate the framing of a disease as a social problem.

As a medical sociologist, I am not simply interested in how social forces shape understandings of health and illness. Nor am I solely interested in examining health disparities or even the social (and the cultural) constructions of health and illness. Rather, I am interested in what diseases mean to groups based on their common cultural and even localized community understandings. With this focus, my research will add to the critical examination of the construction of cultural and community-specific health related information, with the intention of applying such techniques to combating a variety of other health disparities within the Black community. Researching and studying how diseases are framed in culturally relevant ways is interesting in and of itself, but examining them so that these tactics can be used to decrease health disparities is even better.

Social Marketing:

Sociologists have argued for more of a place in marketing for almost 50 years. For example, in 1959, Johanssen wrote an article in the *Journal of Marketing*, explaining the application of sociology to marketing with the intention of encouraging sociologists to increase their roles within this field. Johanssen's (1959) contention was that sociologists could offer great insights into marketing because we analyze cultural shifts and consumer behavior. In that same issue, Robert Bartels wrote, that, "while variously classified, both sociologists and marketing men [and women] are *social scientists*... The study of marketing is as 'social' a science as the study of society. If sociologists and marketing men [and women] would work jointly on common problems, their differences

in viewpoint would diminish" (1959: 37-38). Not only is sociology applicable to the general study of marketing, but sociology is even more relevant to the subfield of social marketing.

As sociologists, we are interested in social problems, and as the sixth chapter noted, social marketing is one technique used to tackle a social problem. Social marketing campaigns utilize traditional marketing techniques to influence a behavior change. Throughout this dissertation, I noted how The Balm in Gilead initiated the Black Church AIDS movement. I described how The Balm was organized and explained why, prior to The Balm, a number of Black churches were hesitant to focus on AIDS. Through its understanding of the ways in which the Black Church viewed AIDS, The Balm reconciled scientific facts about AIDS as well as the Black Church's social and cultural constructions of AIDS and created audience-specific AIDS information. The next step was for this information to make it to the churches.

As described above, my respondents felt that AIDS information was not being produced for the Church. Educational information contained sexually explicit content as well as references to drug use – material that did not befit a religious institution. The first step in social marketing campaigns is to know the audience and their needs. Pernessa Seele commented to me several times that she "knew the Black Church." Based on her understanding of the Black Church, The Balm was able to create information that resonates with this audience. The Balm in Gilead utilizes Biblical quotes and tales that stress Christian obligation and duty. I also uncovered five themes through my interviews and content analysis that resonate with Black churches: prayer, love, responsibility to care for others, acceptance, and forgiveness. Based on these themes, The Balm creates

materials and campaigns that effectively market AIDS awareness and convince churches to develop ministries. The Balm also emphasizes that the *Christian* duty of churches is not only to address AIDS, but, as the Black community's most influential institution, to assume civic responsibility for its congregants and community.

It is interesting to note that The Balm not only utilizes social marketing techniques to encourage churches to tackle AIDS, but it also encourages Black Churches to utilize similar techniques to promote their own AIDS education programs.
The Black Church's understandings of AIDS are framed by both its role within the Black community and by the experiences of Blacks in the U.S. The Balm in Gilead has an understanding of this – they know their audience – and as a result, they can target this community.

Chapter Six also examines how the disease has become commodified and then sold. This chapter examines the process by which this occurs and takes into account the cultural norms, values, and constraints in which AIDS knowledge has been created and marketed. Sociologists can greatly benefit from the study of social marketing as social marketers create and market social problems. Social marketing literature tends to overlook the process by which a social problem is created. Sociology tends to overlook social marketing altogether. My hope is that this dissertation would be able further to bridge these two schools of thought.

The Social Construction of a Social Problem:

In the end, this dissertation concerns the social construction of knowledge. As I mentioned in the introduction, this research began with my concern for why and how Black churches began to confront the AIDS epidemic. I found that prior to The Balm in

Gilead, AIDS was not constructed as a social problem for the Black Church. The Balm took existing information and reconstructed it based on the Black Church's understandings of AIDS. The social construction of knowledge examines how social realities and knowledges are created and constructed (Berger and Luckmann 1966). Not only has AIDS been socially constructed, but the responses to AIDS have also been constructed.

The concept of social constructionism has been criticized because it is not clear what is being socially constructed, and when these constructions end (Hacking 1999). In this dissertation, I discuss how the larger society, the Black community, the Black Church, and medical science have constructed AIDS. The Balm in Gilead takes all of these constructions into account when it reconstructs AIDS as a social problem – removing medicalized jargon and the stigmas associated with AIDS – for the Black Church.

Spector and Kitsuse (1987) argue that difficulty in the study of social problems stems from the inability of scholars truly to research and define a social problem. They maintain, "The central problem for a theory of social problems is to account for the emergence, nature, and maintenance of claims-making and responding activities. Such a theory should address the activities of any group making claims on others for ameliorative action, material remuneration, and alleviation of social, political, legal, or economic disadvantage (Spector and Kitsuse 1987: 76). In the end, this dissertation is not a study of AIDS in the Black Church, but rather the construction AIDS as a social problem for the Black Church. In fact, as claim makers (Spector and Kitsuse 1987) Seele

and The Balm in Gilead not only constructed a social problem, they constructed the response to this social problem, and, in fact, they even constructed their audience[71].

In addition to examining how The Balm has constructed AIDS, what is also of particular interest are the constraints surrounding the construction of a social problem. As detailed throughout the dissertation, The Balm in Gilead cannot construct just any AIDS information or construct AIDS as just any type of social problem – it has to be an audience-specific social problem. These facts are supposed to be value free and "purely" scientific (Epstein 1996). These facts are then taken, interpreted, and reproduced to make them group specific. In the process of reframing and reproducing AIDS, The Balm puts AIDS within a moral and religious context as a means for addressing AIDS. Traditionally, AIDS activists have tried to take religion out of AIDS discourse, as religion was used as a means for discrimination. The Balm, on the other hand, uses religion as a means through which to encourage churches to address AIDS. The Balm constructs a new version of AIDS, and The Balm then entrusts these churches to

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[71] The Balm recreated its idea of what the Black Church is and the roles it should perform within the Black community. In fact, an entire social movement was created based on Seele's construction of the Black Church and the role that religion plays throughout the African Diaspora. As I explained in the introduction, the Black Church is made up of seven Black denominations that were born out of the experiences of Blacks during slavery and in freedom (Lincoln and Mamiya 1994). As was discussed in the third chapter, the Harlem Week of Prayer served as the catalyst for the Black Church Week of Prayer and for the creation of The Balm in Gilead to sustain this campaign. Originally, during the Harlem Week of Prayer, Seele worked with Harlem religious leaders, not necessarily Black, nor Protestant, nor even Christian. When the Harlem Week of Prayer became a national event, it became known as the Black Church Week of Prayer so that Seele – and later The Balm – could focus on this one institution.
The Balm in Gilead expanded its definition of the Black Church during this week of prayer to include all Black religious institutions. Thus, the ideas associated with the Black Church – civic duty, spirituality, community responsibility – have all been applied to Black religious institutions. As a result, The Balm created a collective identity (Polletta and Jasper 2001; Gamson 1996) of "the Black Church."

construct another, even more audience specific version for their particular community or congregation.

Policy Concerns:

Again, it is imperative that my work not solely be used to enhance the field of sociology, but also to help inform future policy previsions. In this section, I focus on two key concerns that I uncovered as a result of my research: the first being funding, with particular focus on Faith-Based Initiatives, and the second concerns public health campaigns.

Funding:

The major challenge facing organizations wishing to provide AIDS services, as well as many other public health services, is funding. Seele explains, "The challenges that I had initially are the challenges that I have now: money. Resources, finances, that's the challenges that I had back then, that's the challenges that I have now" (Seele). Darlene Cheek of The Balm believes that churches are more willing to address HIV/AIDS, "with training, sure, I think they would, cause there are some churches that are doing amazing work, amazing work, that started doing testing programs in their basement, in their church dining rooms. They have gone to the next level of not just prevention, but actively being sources from the community to come in, doing needle exchange and the whole nine yards, and have actually taken a stand against the disease." My respondents felt that more churches would be willing to participate, "but funding, it's hard. It's hard" (Cheek).

As I discussed throughout this dissertation, most respondents did believe that the

Black Church, because of its position within the Black community, is certainly the place for AIDS education and awareness. The funding has become increasingly limited as the competition increases, "the strange thing about the AIDS family, they will know where you will get funding, but they won't tell you" (C. Davis).

The funding for AIDS services are varied – from foundations and private donors, to pharmaceutical companies, government sources, and private health insurance companies – countless billions have gone into the fight against AIDS both globally and internationally. Yet, many would argue that the money is not reaching the people. People need medicine (which can cost upwards of $15,000 a month), housing, food, and a variety of health related services. In addition, AIDS service organizations and groups are overtaxed by the costs of caring for those infected. Even the costs of HIV testing are prohibitive. Providing AIDS education and awareness is also costly. Condoms, dental dams, finger cots, lubricant, brochures, as well as the countless hours of labor involved in putting these materials together is expensive, particularly coupled with the costs of food for AIDS education events, rental space, computers, Internet access, production materials for plays or conferences and workshops. The cumulative costs, coupled with the sheer discomfort many leaders feel about providing AIDS education and discussing AIDS in a church, could mean the difference between having an effective ministry and having none at all.

Those ministries examined in my research were all funded either by government grants, church funds, or, in the case of Rev. Davis at Timothy Baptist Church, paid for out of pocket. Angela Griffin points out, "we received a small grant last year from the city of New York. I think they gave us a $13,500 'mini grant', but… as a whole, the

Church has been the primary 'person' that supported us. We don't receive any other funds for what we do." Other, wealthier churches such as Rev. Jones' Harlem based church or Emmanuel Baptist Church do not have as difficult a time providing funding for their AIDS ministry. As Pastor Trufant stated above, members of the AIDS ministry at Emmanuel plan to make a trip to offer support to an AIDS service organization in South Africa.

Nevertheless, I agree with Latrice Wactor when she says, "I think they address [AIDS] because they genuinely want to. I don't think they address it for the money, because it's really not that much money." In addition, I concur with Angela Griffin who says, "I don't think that funding keeps you from having a ministry, I just think that with [no] funding involved, it just takes more creativity" (Griffin). This creativity includes partnering with other churches, like Jennifer Smith's AME church in the Bronx which works with other churches in Brooklyn and Harlem to organize workshops, conferences, and other events. This creativity also includes partnering with community organizations, whether locally, or in the case of Emmanuel Baptist Church, internationally. These AIDS ministry leaders have also partnered with ministries, such as a drama ministry which might produce plays like Sundi Lofy's "Love Me Through It." For as Rev. Trumpet says, "don't wait for the government and foundations. I think that sometimes you go tot step out and do it for yourself and for your people and let everything else come into divine order." But ultimately, the most basic and cost effective way of addressing AIDS in the Black Church and possibly reducing stigma is to do what Seele originally tried to do with her march around Harlem Hospital: bring AIDS awareness to religious institutions so that they can simply pray for those suffering for HIV and AIDS. But when funding issues

were addressed during the interviews, most often, Bush's Faith-Based Initiatives were brought up.

Faith-Based Initiatives – a Brief History and Informant Responses:

The most well-known federal AIDS program has probably been the Ryan White AIDS CARE Act[72], which was authorized more than 10 years prior to Bush's Faith-Based Initiatives and was recently reauthorized on September 30, 2005. This act was mandated by the government to provide care and treatment to those living with AIDS and provided billions for health care, food, and housing, but because AIDS patients are living longer, healthy lives, the funds spent for AIDS service programs have not kept up with the greater demand for funds. The HIV infection rate has remained relatively the same but people have lived longer with HIV and AIDS, thus requiring more funds than were being distributed. As a result, AIDS service organizations were skeptical of and angered by Bush's 2001 Faith-Based Initiatives. These initiatives allowed more religious institutions to apply for these limited AIDS services funds. These initiatives, however, did not necessarily increase the funds being allocated.

Faith-Based Social Initiatives are forms of social and community support that religious institutions such as mosques, churches, and synagogues provide to help solve social problems (Black, Koopman, and Ryden 2004; Formicola, Segers, and Weber 2003). For some, religious institutions are a main source of support and guidance. This support can include building and funding elementary schools, providing health care,

[72] The Ryan White CARE Act was enacted in 1990 after the death of AIDS activist Ryan White that same year. This act is funded through the HIV/AIDS Bureau of the Health Resources and Services Administration, a division of the Department of Health and Human Services. It was reauthorized in both 1996 and 2000, and, most recently in 2005. This act was designed to meet the health needs of those in most dire need of health related services.

sponsoring local neighborhood watch programs, operating soup kitchens, providing clothing for the needy, and building low income housing and neighborhood renewal. For quite some time, religious and community leaders and politicians alike have argued for more governmental support for their programs because of the positive impact they have on their communities. When most people think of faith-based social initiatives, however, they think of the federal funding that President George W. Bush allows churches and other religious institutions to apply for to support their charities and community works. These initiatives encourage faith-based institutions to apply for and receive federal funds from the following departments: the U.S. Departments of Education, Labor, Health and Human Services, Housing and Urban Development, Justice, and Agriculture, and the U.S. Agency for International Development, as well as state and local monies (Black, Koopman, and Ryden 2004; Formicola, Segers, and Weber 2003).

On January 29, 2001, President Bush issued Executive Order 13199, which established the White House Office of Faith-Based and Community Initiatives. President Bush, a born-again Christian, strongly believes in the power of communities of faith to solve social problems and change lives for the better (Formicola, Segers, and Weber 2003). This office, under the executive branch of the federal government, oversees the government's efforts in encouraging both religious and community-based institutions to supply social services as well as provide financial, and even in some cases, technical support for social service programs. Another function of this office is to make sure the policy developed is in accordance with the President's goal to encourage charity and community action, and to identify and replicate successful community service programs. With these initiatives, Bush contended that religious institutions with social service

programs should be eligible to apply for federal funds just like non-profit and secular institutions. According to Bush, faith-based organizations are just as equipped as other community-based organizations to provide services and support for their communities (Black, Koopman, and Ryden 2004; Formicola, Segers, and Weber 2003).

But federal support of religious institutions is nothing new. A number of religious institutions – such as the Salvation Army and Catholic Charities – have received federal funds for decades. In fact, discussions of federal funding of faith institutions did not begin during the Bush Administration, but began with President Bill Clinton's Welfare Reform (Black, Koopman, and Ryden 2004; Formicola, Segers, and Weber 2003).

In 1996, then-President Clinton reduced government funding for welfare, limiting the amount of time people can spend on welfare as well as their eligibility to receive funds. Recognizing that many people may increasingly turn to religious institutions for support, Section 104 of the welfare reform law, the Charitable Choice provision, was sponsored by Senator John Ashcroft (R-MO) and was implemented (Formicola, Segers, and Weber 2003). This was designed to remove barriers to allowing religious institutions to apply for federal welfare funds. It also stressed the separation between church and state, ensured protection of the clients of these religious charities, and allowed these religious institutions to maintain their religious beliefs without government intervention. Charitable Choice quickly became part of federal law, but most people did not focus on these provisions, and they were largely ignored because of the larger issues surrounding Welfare Reform.

For the most part, Charitable Choice fell between the legal cracks until the 2000 presidential campaign, where candidates Al Gore and George W. Bush both supported

the ideas behind Charitable Choice and the funding of religious institutions for social service programs (Formicola, Segers, and Weber 2003). Immediately, when elected to office, Bush established the Office of Faith-Based Community Initiatives to implement the Charitable Choice provision. Bush's opponents, however, latched onto this policy, rallying against Faith-Based Initiatives.

The main arguments against Faith-Based Initiatives fall within three camps (Formicola, Segers, and Weber 2003): 1. "The separation between church and state" as mandated by the First Amendment. The government really does not have any way of knowing if, in the implementation of social service programs, religious institutions are proselytizing; for example, they may encourage prayer before meals, or distribute religious paraphernalia during health fairs. 2. Also, a number of religious leaders fear that receiving federal funds will bring unwanted attention from the federal government into church practices, challenging their religious freedoms. 3. Fears exist that the government will discriminate against non-traditional or non-Christian religious groups such as the Hare Krishnas or the Nation of Islam in the distribution of funds.

My respondents had many reservations concerning these initiatives. Darlene Cheek of The Balm in Gilead asks:

> Is the money there, because I'm not seeing any? I've not heard of any money in the faith-based initiative that Bush has established… There was never money in the faith-based initiative. I don't think there was ever money there. I think that was a good political ploy. It was good media coverage. It was good attention grabbing for people to say, 'wow, Bush is going to help us fight this disease, we'll vote for him because he's gong to help us,' and it never was real. (Cheek)

Ms. Cheek was not the only one who expressed such sentiments; for the most part, my respondents either believed that there was no money at all, or if there was, that the money was a political ploy.

But most of those interviewed feared governmental intrusion if they received these funds because as Sullivan notes, "you have to be careful of who you get in bed with. You have to understand that you deal with federally funded or federally received grants, you are obliged to follow their rules for the grants. That is one of the agreements." Expressing a similar sentiment, Rev. Trumpet maintains: "you know the Church doesn't want money and then folk got to try to tell them how to use it. And then [the government] tells them you know well, you can't talk about this, you can't talk about that. It's a compromise as far as I'm concerned… I can't say as a preacher that I can compromise on the Word. I can't." There are, indeed, a number of requirements that churches and other religious institutions must face in order to apply for and receive these monies, and, according to Dr. Moon-Howard, "It may be that a lot of our churches hadn't met those requirements." Rev. Trumpet notes, "Government funding without strings attached, can we have that? Can we have government funding without strings attached?" Latrice Wactor agrees, "you give folks money, especially the smaller churches, and there were so many conditions, so to speak… One of the biggest conditions, especially for a smaller church… is it was on a reimbursement basis, meaning you would have to spend the money and then get reimbursed, a lot of smaller churches don't have the money to do that" (Wactor). There are program and teaching requirements. In addition, there are also a number of other requirements once these monies are received, such as filing the proper taxes, and, especially, keeping the proper records (Formicola, Segers, and Weber 2003). But regardless of these requirements, there is support offered to those applying for these funds, such as sample grant applications and even officials who provide assistance in applying for these grants.

Ultimately, according to David Kuo (2006), a conservative Christian who spent three years as a high-ranking official in the Office of Faith-Based Initiatives, these fears are warranted. Kuo says that Bush used these initiatives to gain the support of both Christians and minority Democrats (Kuo 2006). In fact, Kuo (2006) contends that the Clinton administration spent $20 million a year more on these initiatives than Bush.

Public Health Concerns:

As my research has shown, community-based organizations and religious institutions can play a major role in health awareness and promotion. If an organization can encourage a socially conservative institution such as the Black Church to promote AIDS awareness and create an international movement, other less stigmatizing health and political issues can also be addressed. Public health officials often focus on cultural competence in order to decrease health disparities. Creating and framing disease is all well and good, but, in the end, not only does information have to make it to the target audience, but groups also may need help with getting their own social service programs off the ground.

Oftentimes providing technical assistance to an organization that wants to create a health awareness campaign can also be invaluable. Wactor maintains,

> [If] they don't have a good foundation, they don't know what to do, where to go. They don't know what deliverables they should have. So it's a catch-22 situation, [if monies were available] one of the conditions upon receiving the money, is maybe if you're accepted for the grant you have to attend a one-week workshop on how to spend this money. Or provide some sort of technical assistance for churches, cause it's a waste.

As I described in Chapter Three, Seele went from being someone who created two AIDS awareness marches to founding an organization to provide technical assistance and training to churches and other religious institutions wishing to work with the Black

Church to promote AIDS awareness. In fact, The Balm uses most of its funding to back their training and technical assistance programs. One cannot simply tell churches that they should have an AIDS ministry or to address AIDS during a prayer service; AIDS is a taboo topic and must be addressed in such a way so as not to "turn off" the potential audience and even the educators with information and materials that are considered too "offensive" to be addressed within a church. The Balm provides not only AIDS education workshops but church-appropriate ways that address issues relating to AIDS in a manner befitting the Church's beliefs. As I discussed throughout this dissertation, The Balm produces materials and information in non-judgmental and informative ways that are not considered offensive by many religious leaders. More important, The Balm also shows these churches and other organizations how to create AIDS awareness workshops and events.

There are a number of things that can occur when approaching religious institutions about addressing any health or social issue. The first is not to necessarily create the materials for this organization but provide them with basic facts and let them edit the material in any way these churches or groups feel is appropriate for their constituents, congregants, or clientele. The second is to be sensitive of the particular social histories that these churches face when they confront social issues such as Black Church views of sexuality and homosexuality or drug use.

Sometimes information is not enough, and supplies and infrastructure are needed, as was the case for The Balm in Gilead and their Africa Initiative, a project in which The Balm worked with religious institutions in five African nations to encourage AIDS awareness programs. Mugarura believes, "We'll get a way of working with them to

design programs and to support them to implement the design of the program… The focus has been to empower the Africans to lead themselves, to empower the Africans to design and implement programs that are relevant to their needs." They do this by providing basic education, literature, money, as well as providing office space, telephones, computers, Internet access.

The Black Church Continues the Movement:

In June, 2006 The Balm in Gilead moved its headquarters to Richmond, VA, and opened up branches in New York City, Washington, DC, and Tanzania. Not only will The Balm's AIDS services expand, so too will the services provided by the various AIDS ministries with which I spoke. Many of the ministry leaders from the churches that I interviewed spoke at great length of the services and events they plan to have at their church. Angela Griffin explains: "We'd like to have an AIDS awareness day… we would like to have a short skit that generates discussion or show another film, and generate some discussion." Rev. Claudette Davis of Timothy Baptist Church hopes to, "have a connection so that the church can either sponsor testing, have a place where we can meet and discuss the AIDS issues with individuals on a consultation basis." Most churches said that they would like to provide additional AIDS education, such as "HIV 101" (Wactor) as well as a number of other education and training forums.

The expansion of The Balm in Gilead, as well as the emergence of AIDS ministries in Black Churches across the U.S. and the world, has shown that the Black Church AIDS movement is continuing to grow. Past research that addresses AIDS in the Black Church has discussed what the Black Church has not done (Dalton 1989; Fullilove

and Fullilove 1999), why it has not been done (Cohen, 1999), and what needs to be done (Weatherford and Weatherford, 1999). I examined the ways in which a CBO with the hopes of reaching the larger Black community takes medical knowledge and turns it into religious knowledge for the Black Church,. Thus, the CBO, not an 'outside' medical organization, is attempting to equip the most trusted organization within the Black community to spread knowledge and information pertaining to HIV to the Black community.

In part because of The Balm in Gilead, other organizations are reaching out to the Black Church to promote health awareness. Seele observes, "I think that many of them, many people have been inspired to work with Black Churches because of The Balm and that's very good because we need organizations working in their community supporting the African American churches" (Seele). Also, as a result of The Balm in Gilead, churches and other community-based organizations will see the Black Church as a place for not just AIDS education and awareness, but an acceptable venue to address other diseases. Rev. Ware concludes:

> I think this whole pendulum thing is moving back toward community involvement in all of the churches. Black Churches are aware of the health situation because of the disparities within the African American community, so you have ministers who are trying to address that in one way or another, to get some people to go and get an annual checkup to get a physical, to do those kinds of things, to pay attention to their blood pressure medicine, to eat like they are supposed to eat. You know, you are diabetic, do what you are supposed to do. I think that has become a part of many of the conversations in many churches because of the need. I really think it has. (Ware)

"Meeting churches where they are" has become a key phrase within this movement – part of the harm reduction model described by Geneva Musgrave of Emmanuel Baptist Church. Churches had AIDS ministries before The Balm in Gilead

and I believe that many would have organized ministries without The Balm, but what The Balm did was to create a national movement whereby they made AIDS something that could be discussed in the Church, and then provided the Church with the means with which to do it.

As I mentioned in Chapter Three, Tilly (2004) noted that social movements had three characteristics, an "organized public effort… political action [and] commitment on the part of themselves and/or their constituencies" (3-4), with the latter probably being the most important. The Black Church AIDS movement has been able to sustain itself because of the "commitment on the part of" the Black Church, its leaders and congregants, as well as the ongoing efforts of The Balm in Gilead and other organizations such as Harlem Congregations for Community Improvement, the Black Leadership Commission on AIDS, The Black AIDS Institute, and a slew of other community-based organizations around the country and around the world. Though AIDS in the Black community is continuing to increase, so are the varying responses to the AIDS epidemic. With the inclusion of churches and other religious institutions in the battle against HIV in the Black community there is bound to be an increase in AIDS awareness, and more important, compassion on behalf of those living with AIDS.

As this movement continues, The Balm in Gilead also has to re-shape itself. The re-shaping of foci in social movement organizations is nothing new. For example, in 1938, Franklin D. Roosevelt founded the National Foundation for Infantile Paralysis in order to raise funds for a polio vaccine (March of Dimes 2007). In 1952 Jonas Salk, a CCNY graduate, discovered the vaccine for polio. In 1962 an oral vaccine was developed with the help of funding from The National Foundation. With the virtual

eradication of polio in the U.S., The National Foundation changed its name to The March of Dimes[73] in 1979 and shifted its focus to infantile health (March of Dimes 2007). The Balm has had a similar experience.

The Balm in Gilead began as a prayer initiative in Harlem. Seele's initial goal was not about education, but bringing awareness and compassion to Harlem religious institutions. Like the March of Dimes, she succeeded in this initiative and Harlem religious institutions were praying for people with AIDS. In order for The Balm in Gilead to sustain itself, it had to shift its focus to providing AIDS education and expanded from Harlem to become a national organization. Soon churches began to seek education support, and The Balm was there to address these issues. Now, The Balm is an international organization, and when it became clear that New York City churches had a critical mass of AIDS ministries, The Balm moved its headquarters to Richmond, VA.

AIDS in the Black Church is just the beginning for The Balm in Gilead. Seele maintains, "I think that HIV will continue to be our focus for a long, long time, but when you look at all the other diseases in our community, it is important that we utilize lessons learned in terms of how we begin to address other problems" (Seele). As mentioned previously, in 2005, The Balm began the Intimate Sessions for Informed Sexuality (ISIS), where they address HPV and cervical cancer, along with open discussions where women reconcile their sexuality with their spirituality; eventually, The Balm would like to spread out to address other diseases, encouraging the Black Church to take on other health issues. Seele points out, "Somebody is dying of cervical cancer – they are not dying of AIDS, some are dying from Hepatitis C –they are not dying of AIDS. Someone is dying

[73] The March of Dimes is named after its campaign to encourage people to send dimes to the White House to help support The National Foundation.

from cardiovascular disease, I think that we have laid a track, a public intervention that we need to utilize in other diseases" (Seele). In fact, this past October, what was once the Black Church HIV/AIDS Training Institute became known as the Black Church HIV/AIDS and *Other Health Disparities* Training Institute. Similarly to the March of Dimes, for the Black Church AIDS movement to continue it has to reshape its goals and focuses.

Conclusion:

This dissertation examined how a community-based organization, The Balm in Gilead, works with the Black Church in order to promote AIDS awareness. Pernessa Seele organized The Black Church AIDS movement, and created an organization, The Balm in Gilead, to maintain this movement. I looked at how AIDS was socially constructed by both the larger society and by the Black Church. By examining the Black Church's social construction of AIDS, The Balm in Gilead took already constructed AIDS knowledge and reframed it to fit in with the Black Church's social construction of AIDS, thereby addressing AIDS knowledge in a way that is not only acceptable to the Black Church, as an institution, but also to the individual churches with which the Balm works to reframe AIDS. Once this knowledge was reframed, it was marketed to the Church.

I have the utmost respect and admiration for Pernessa Seele, her employees – both former and current – at The Balm in Gilead, as well as the AIDS activists, religious leaders and congregants whom I interviewed. I deeply appreciate the opportunity I was given to spend time at The Balm, as well as the access this experience allowed me to the

world of Black Church AIDS activism. I hope that this dissertation is a true testament to their work and dedication in addressing one of the most important health-related social problems facing African Americans. In the end, the purpose of this dissertation was neither to sing the praises of The Balm in Gilead – though certainly accolades are in order to Seele and the staff at The Balm – nor of those ministry leaders, pastors, volunteers, and activists. Nor was the aim to focus solely on AIDS and the Black Church. As stated in the first chapter, I became interested in examining the steps that the Black Church was taking to address HIV/AIDS among African Americans. As mentioned, previous research contended that the Black Church was doing very little in terms of AIDS education; as a result, I set out to explore what was happening. I found that the Black Church is addressing AIDS. It has become a social problem among Black churches, and this was in part due to the work of The Balm in Gilead.

This dissertation dealt with a number of different topics: social movements, identity, activism, race, discrimination, stigma, homosexuality, sex, gender, drug use, urban communities, religion, sickness, disease, health, the Black Church, and AIDS. Yet, in the end, this dissertation focused on a problem and the steps taken to solve this problem. It raises numerous questions: Why should the Black Church address HIV/AIDS – it is a religious institution, not a medical one? What do we, as a society, and more specifically, as the Black community, have to gain by Black religious institutions addressing AIDS? What is the practicality of religious institutions addressing as contentious a disease as AIDS? How are churches providing AIDS education within their own congregations and communities? This dissertation was never meant to answer any of these questions. Future research could attempt to answer these questions, or

should look at the utilization of Balm in Gilead materials and techniques by Black Churches. Another interesting project will be to see how material is created for non-Christian groups, such as Muslims in the various African nations in which the Balm works, as well as the Nation of Islam here in the U.S.

The one question I will provide an answer to will be the one I am most frequently asked – and interestingly, the one I never set out to answer: Is The Balm successful? Much of this has to do with how one measures success; if one's measure of success is the decrease in rates of HIV/AIDS among Blacks, then the answer is no. All one has to do is simply to look at the rates of HIV/AIDS among Blacks and see that the rates have increased as of the late 1980s – when the Black Church Week of Prayer began. The process is slow, and it is difficult to know whether the rates would have been worse had The Balm not come into existence. The Balm is getting AIDS information, recreating it for Black churches with the hopes that Black churches will take the next step and recreate it for their individual congregations. The Balm in Gilead is not providing AIDS information to the community itself, but equipping the community with what The Balm feels are the proper tools to promote AIDS awareness and education within its individual communities. This is a very long process and since most churches were not on board in the beginning, I think it will take years before we see any major results.

Then again, if the measurement of success is whether The Balm accomplished its goals – both original goals and current goals, then I would have to say yes, The Balm in Gilead has been extremely successful. According to The Balm's mission statement, "the mission is to improve the health status of people of the African Diaspora by building the capacity of faith communities to address life-threatening diseases, especially HIV/AIDS"

(The Balm in Gilead 2006). The Balm has been able to encourage Black churches and other religious institutions in the U.S. and abroad to mobilize against AIDS, and that has been no easy feat. Again, Pernessa Seele's initial goal was to get churches to pray for those with AIDS and to create a sense of awareness and acceptance within Harlem churches. As Canon Williams said: "Today, right now, as we speak, in Harlem, there is not one major church, not one, that does not have some kind of AIDS program… And anybody who is opposed to the work of AIDS education and prevention would be strongly censored by public opinion if they were to 'come out of the closet.' We've just turned the circle completely from night to day."

Epilogue

Two years have gone by since I first began my research of The Balm in Gilead and the Black Church's response to the AIDS epidemic. Much has happened, such as the prolonged Iraq War, government cutbacks and arguments concerning same sex marriage, as well as the open support of Black Church leaders for gays and lesbians, along with their acknowledgement that the Right Wing is using homophobia within the Church to "divide and conquer." More important, many major events have happened in the life of The Balm in Gilead while I was completing my dissertation.

In June of 2005, about three months into my ethnography, Douglas Parker, a 16-year volunteer with The Balm in Gilead, died. We had many wonderful conversations; among them he provided me with a very detailed history of The Balm in Gilead, how the organization has changed, and the work it has accomplished. I did not cite or reference him in this dissertation. I truly regret not formally interviewing him, but I owe much of my understanding of The Balm to Doug.

In April 2006, I was saddened by the death of another member of The Balm in Gilead family, Canon Frederick Williams. I found out about the death of Canon Williams during another interview with a respondent. The Canon died unexpectedly of a massive heart attack. His *New York Times* obituary headline read: "Frederick B. Williams, 66, Bold Moral Voice in Harlem Dies." Unlike Douglas Parker, I was able to interview the Canon - about a week before his death.

There were also a number of changes that took place within The Balm in Gilead as an organization. June 30, 2006, was the last day that The Balm in Gilead resided in their

offices on the 4th floor of the Busch Building on 42nd Street in Manhattan. In May, Seele informed the staff that The Balm in Gilead would be relocating to Richmond, Virginia. The headquarters of The Balm will be in Richmond while they open up additional offices in Washington DC and New York City (currently in operation on the 7th floor of the Busch Building), in addition to an office in Tanzania. Thus far, only one staff member, in addition to Seele, has relocated to the Richmond office, while four remain in the New York satellite office. All of the other staff members have left The Balm. About this move, Seele stated:

> It is time to go… I could not have built this institution nowhere else except for New York. There was not a Preston Washing or a Canon Williams, none of the ministers. What I had here were the stars of Black Church in the World. Jim Forbes, Riverside Church, Abyssinian was here, Wyatt T. Walker were here. Just the Black celebrity power of the country was here and they all rallied around me and helped me to move the message, more what I was doing, so I could not have done it without here… But our headquarters are going to be in Richmond, where the artery of the Black Church is (Seele).

Appendix A:

Sample Interview Questions:

Each interview was very conversational in nature. I had a separate set list of questions compiled for each respondent prior to the interview depending on if they were an AIDS activist, a Balm employee, affiliated with a CSP, or with a church. The questions listed below are a sample of the types of questions that I asked my respondents. These questions varied depending on the position of the respondent in their respective organization.

- How long have you lived in New York?
- Would you describe yourself as religious or spiritual?
- How long have you attended/worked at your church? What are some of the changed you've witnessed?
- How long have you worked for The Balm?
- Where were you born and raised?
- What is your educational background?
- What have been your experiences with HIV/AIDS?
- How has AIDS affected your community?
- How important, do you believe, the Black Church is to the Black community?
- Do you think that by addressing AIDS, your ministry will expand to address other health issues or social problems?
- How long have you worked at The Balm?
- Can you describe your responsibilities or duties at The Balm?
- What types of services do you provide to churches?
- Can you please describe your ministry?
- How have church leaders responded to your ministry?
- How has the congregation responded to your ministry?
- How do you participate in the Week of Prayer?
- What types of AIDS information do you provide?
- What types of services do you provide?
- How do you provide AIDS education or awareness?
- What are the goals of your ministry?
- Can you describe your church's congregation?
- As the pastor, what types of AIDS materials do you allow to be distributed within your church?
- Can you talk about your experiences with drug use, sex, and homosexuality?
- What are some of the challenges you have faced while at The Balm?
- How has your church responded to your ministry?

- How do you encourage churches to look past the stigma of AIDS as being a White gay man's disease?
- How do you think churches address issues of sexuality? What about issues of homosexuality? Issues of drug use?
- What are your views on abstinence versus safer sex?
- Does you distribute condoms?
- When did you first hear about The Balm?
- How long have you worked for The Balm?
- How does The Balm make AIDS an acceptable topic for Black Churches?
- Is the Black Church the place for AIDS awareness?
- What types of materials do you find to be the most effective?
- What would you like to see happen with the materials that you produce?
- Can you talk about why churches are more willing to address HIV now? What has changed over the years?
- How much of a role does homophobia play in getting churches to address AIDS?
- Can you talk about the kinds of technical support The Balm provides?
- How much funding do you receive?
- Where do you receive your funding?
- How have you been impacted by Bush's Faith-Based Initiatives?
- How has your church changed as the result of having an AIDS ministry?
- What do you think of The Balm?
- How do you work with The Balm?
- Do you work with other AIDS service organization besides The Balm?

Bibliography:

Abdulrahim, Dima. 1998. "Power, Culture and the 'Hard to Reach': The Marginalization of Minority Ethnic Populations form HIV Prevention and Harm Minimisation. Pp. 37-53 in *Meddling with Mythology: AIDS and the Social Construction of Knowledge,* edited by R.S. Barbour and G. Huby. New York, NY: Routledge.

AfricanLanguages.com. 2005. "AfricanLanguages.com." Retrieved October 30, 2005. (http://africanlanguages.com/.)

Ajen, Nii. 1998. "West African Homoeroticism: West African Men Who Have Sex with Men." Pp. 129-140. in *Boy-Wives and Female Husbands: Studies of African Homosexualities,* edited by S.O. Murray and W. Roscoe. New York, NY: St. Martin's Press.

Alonzo, Angelo A, and Nancy R. Reynolds. 1995. "Stigma, HIV and AIDS: an Exploration and Elaboration of a Stigma Trajectory." *Social Science and Medicine* 41 (3): 303-315.

Altheide, David L. and John M. Johnson. 1994. "Criteria for Assessing Interpretive Validity in Qualitative Research." Pp. 499 in *Handbook of Qualitative Research*, edited by N.K. Denzin and Y.S. Lincoln. Thousand Oaks, CA: Sage Publications.

Amory, Deborah P. 1998. "*Mashoga, Mabasha,* and *Magai*: 'Homosexuality' on the East African Coast. Pp. 67-90 in *Boy-Wives and Female Husbands: Studies of African Homosexualities,* edited by S.O. Murray and W. Roscoe. New York, NY: St. Martin's Press.

Anderson, Elijah. 1999. *Code of the Street: Decency, Violence, and the Moral Life of the Inner City*. New York, NY: W.W. Norton & Company, Inc.

Andreasen, Alan R. 2005. *Social Marketing in the 21st Century*. Thousand Oaks, CA: Sage Publications.

Andreasen, Alan R (Ed.). 2001. *Ethnics in Social Marketing.* Washington DC: Georgetown University Press.

Atkinson, Paul and Martyn Hammersley. 1994. "Ethnography and Participant Observation." Pp. 248-261 in *Handbook of Qualitative Research*, edited by N.K. Denzin and Y.S. Lincoln. Thousand Oaks, CA: Sage Publications.

Axtell, Sara. 1999. "Disability and Chronic Illness Identity: Interviews with Lesbians and Bisexual Women and Their Partners. *Journal of Gay, Lesbian, and Bisexual Identity* 4(1): 53-72.

Babb, Sarah. 1996. " 'A True American System of Finance': Frame Resonance in the U.S. Labor Movement, 1866 to 1886." *American Sociological Review* 61(6): 1033-1052.

The Balm in Gilead. 2006. "Mission." New York, NY: The Balm in Gilead, Retrieved January 9, 2007. (http://www.balmingilead.org/about/mission.asp).

The Balm in Gilead. 2006. "The 17th Annual Black Church Week of Prayer for the Healing of AIDS." Pamphlet. New York, NY: The Balm in Gilead, Inc.

The Balm in Gilead. 2005. "The ISIS Project City Tour Intimate Sessions." New York, NY. The Balm in Gilead, Retrieved September 20, 2005. (http://www.theisisproject.org/city_tour/).

The Balm in Gilead. 2004. *Blessed are They that Comfort: An Introduction to HIV/AIDS for Black Congregations.* New York, NY: The Balm in Gilead, Inc.

The Balm in Gilead. 2003a. *The Black Church HIV/AIDS Care Handbook.* New York, NY: The Balm in Gilead, Inc.

The Balm in Gilead 2003b. *The Black Church Week of Prayer for the Healing of AIDS 2003 Training Manual.* New York, NY: The Balm in Gilead, Inc.

The Balm in Gilead 2003c. *The Black Church Week of Prayer for the Healing of AIDS Planning Guide 2003.* New York, NY: The Balm in Gilead, Inc.

The Balm in Gilead. 2001. *Extending Grace! An AIDS Ministry Handbook.* New York, NY: The Balm in Gilead, Inc.

The Balm in Gilead. 1997. *Though I Stand At the Door and Knock: Discussions on the Black Church Struggle with Homosexuality and AIDS.* New York, NY: The Balm in Gilead, Inc.

The Balm in Gilead. 1994. "The African American Clergy's Declaration of War on HIV/AIDS."

Barber, Bernard. 1962. "Resistance by Scientists to Scientific Discovery." Pp. 539-556 in *The Sociology of Science*, edited by B. Barber and W. Hirsch. New York, NY: The Free Press of Glencoe.

Barbour, Rosaline S. and Guro Huby. Eds. 1998. *Meddling with Mythology: AIDS and the Social Construction of Knowledge*. New York, NY: Routledge.

Barbour, Rosaline S. and Guro Huby. 1998. "Introduction: AIDS: From the

Specialised to the Mainstream." Pp. 1-21 in *Meddling with Mythology: AIDS and the Social Construction of Knowledge*, edited by R. Barbour and G. Huby. New York, NY: Routledge.

Barker, Kristin. 2002. "Self-Help Literature and the Making of an Illness Identity: The Case of Fibromyalgia Syndrome (FMS)." *Social Problems* 49(3):279-300).

Bartels, Robert 1959. "Sociologists as Marketologists." *Journal of Marketing* 24: 37-40.

Basil, Michael D. and William J. Brown. 2001. "Marketing AIDS Prevention: The Differential Impact Hypothesis Versus Identification Effects." *Journal of Consumer Psychology*, 6(4): 389-411.

Battle, Juan J. and Natalie D.A. Bennett. 2005. "Striving for a Place: Lesbian, Gay, Bisexual, and Transgender (LGBT) People." Pp. 413-445 in *A Companion to African American History*, edited by A. Hornsby. Malden, MA: Blackwell Publishing.

Battle, Juan, Cathy Cohen, Angelique Harris, and Beth Richie. 2003. "We Really Are Family: Embracing Our Lesbian, Gay, Bisexual, and Transgender (LGBT) Family Members." Pp. 93-106 in a special edition on the Black Family in *The State of Black America* Washington, DC: National Urban League.

Baughman, Fred A. Jr. 2006. *The ADHD Fraud: How Psychiatry Makes "Patients" of Normal Children*. British Columbia, Canada: Trafford Publishing.

Baumgartner, Lisa Marie. 2001. "The Incorporation of HIV/AIDS into Identity Over Time." Ed.D. dissertation, College of Education. University of Georgia, Athens, GA.

Becker, Howard S. 1963. *Outsiders: Studies in the Sociology of Deviance.* New York, NY: The Free Press.

Benford, Robert D. and David A. Snow. 2000. "Framing Processes and Social Movements: An Overview and Assessment." *Annual Review of Sociology* 26(2000): 611-639.

Ben-David, Joseph. 1962. "Scientific Productivity and Academic Organization in Nineteenth-Century Medicine." Pp. 305-328 in *The Sociology of Science*, edited by B. Barber and W. Hirsch. New York, NY: The Free Press of Glencoe.

Bennett, Michael and Juan Battle. 2001. "We Can See Them, but We Can't Hear

Them: LGBT Members of African American Families. Pp. 53-67 in *Queer Families, Queer Politic: Challenging Culture and the State,* edited by M. Bernstein and R. Reimann. New York, NY: Columbia University Press.

Berbrier, Mitch. 1998. " 'Half the Battle': Cultural Resonance, Framing Processes, and Ethnic Affectations in Contemporary White Separatist Rhetoric." *Social Problems* 45(4): 431-450.

Berger, Peter L. and Thomas Luckmann. 1966 (1989). *The Social Construction of Reality: A Treatise in the Sociology of Knowledge.* New York, NY: Anchor Books, Doubleday.

Best, Joel. 1987. "Rhetoric in Claims-Making: Constructing the Missing Children Problem." *Social Problems* 34(2): 101-121.

Biddle, Nina, Lisa Conte, and Edwin Diamond. 1993. "AIDS in the Media: Entertainment or Infotainment." Pp. 141-150 in *AIDS: Effective Health Communication for the 90s,* edited by S.C. Ratzan. Washington, DC: Taylor & Francis.

Billingsley, Andrew. 1999. *Mighty Like a River: The Black Church and Social Reform*. New York, NY: Oxford University Press.

Billingsley, Andrew and Cleopatra Howard Caldwell. 1991. "The Church, the Family, and the School in the African American Community. *The Journal of Negro Education* 60(3): 427-440.

Black, Amy E., Douglas L. Koopman, and David K. Ryden. 2004. *Of Little Faith: The Politics of George W. Bush's Faith-Based Initiatives.* Washington, DC: Georgetown University Press.

Blumer, Herbert. 1969 (1998). *Symbolic Interactionism: Perspective and Method*. Berkeley, CA: University of California Press.

Blumberg, Rhoda Lois. 2003. "Civil Rights: The 1960s Freedom Struggle." Pp. 15-21 in *The Social Movements Readers: Cases and Concepts*, edited by J. Goodwin and J.M. Jasper. Malden, MA: Blackwell Publishing.

Blumberg, Rhoda Lois. 1987. *Organizations in Contemporary Society*. Englewood Cliffs, NJ: Prentice-Hall, Inc.

Brandt, Allan. 1987. *No Magic Bulled: A Social History of Venereal Disease in The United States Since 1880.* New York, NY: Oxford University Press.

Brown, Jane D., Cynthia S. Wasnak, and Kim Walsh Childers. 1989. "Family

Planning, Abortion and AIDS: Sexuality and Communication Campaigns." Pp. 85-112 in *Information Campaigns: Balancing Social Values and Social Change*, edited by C.T. Salmon. Newbury Park, CA: Sage Publications.

Brown, Phil and Stephen Zavestoski. 2004. "Social Movements in Health: An Introduction." Pp. 1-16 in *Social Movements in Health*, edited by P. Brown and S. Zavestoski. Malden, MA: Blackwell Publishing.

Brown, Phil, Stephen Zavestoski, Sabrina McCormick, Brian Mayer, Rachel Morello-Frosch, and Rebecca Gasior Altman. 2004. "Embodied Health Movements; New Approaches to Social Movements in Health." *Sociology of Health and Illness* 26: 1-31.

Brown, Phil. 1995. "Naming and Framing: The Social Construction of Diagnosis and Illness." *Journal of Health and Social Behavior* 35: 34-54.

Brumberg, Joan Jacobs. 1997. "Anorexia Nervosa in Context." Pp 110-132 In *The Sociology of Health and Illness*, edited by P. Conrad. New York, NY: St. Martin's Press.

Bolander, David O. and Valerie Law Stodden, eds. 1986. *The New Webster's Dictionary*. New York, NY: Lexicon Publications, Inc.

Booth, Karen. M. 2003. *Local Women, Global Science: Fighting AIDS in Kenya*. Bloomington, IN: Indiana University Press.

Borawski, Elaine A., Erika S. Trapl, Loren D. Lovegreen, Natalie Colabianchi, and Tonya Block. 2005. "Effectiveness of Abstinence – Only Intervention in Middle School Teens." *American Journal of Health Behavior,* 29(5): 423-434.

Bourdieu, Pierre. 1979. "Symbolic Power." *Critique of Anthropology*, 4: 77-85.

Bowser, Benjamin P. 1994. "HIV Prevention and African Americans: A Difference of Class." Pp. 93-108 in *AIDS Prevention and Services: Community-Based Research,* edited by J.P. Van Vugt. Westport, CT: Bergin Garvey.

Bureau of HIV/AIDS Epidemiology. 2006. "New York State HIV/AIDS Surveillance Semiannual Report: For Cases Diagnosed through December 2004." Albany, NY: New York State Department of Health, Retrieved January 9, 2007. (http://www.health.state.ny.us/diseases/aids/statistics/semiannual/2004/surveillance_semiannual_report_2004_december.pdf).

Carruthers, Iva E., Frederick D. Haynes III, and Jeremiah A. Wright, Jr. 2005. *Blow the Trumpet in Zion: Global Visio and Action for the 21st Century Black Church*. Minneapolis, MN: Fortress Press.

Castells, Manuel. 1997. *The Power of Identity*. Malden, MA: Blackwell Publishers.

Centers for Disease Control and Prevention. 2006. "Racial and Ethnic Disparities in Heart Disease Among Women." Atlanta, GA: Centers for Disease Control and Prevention, Retrieved September 28, 2005.(ftp://ftp.cdc.gov/pub/Publications/womens_atlas/03-Section1.pdf).

Centers for Disease Control and Prevention. 2005a. "HIV Prevalence, Unrecognized Infection, and HIV Testing Among Men Who Have Sex with Men – Five U.S. Cities, June 2004 – April 2005." Atlanta, GA: Centers for Disease Control and Prevention, Retrieved January 2, 2007. (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5424a2.htm).

Centers for Disease Control and Prevention. 2005b. "National Diabetes Fact Sheet." Atlanta, GA: Centers for Disease Control and Prevention, Retrieved September 29, 2006. (http://www.cdc.gov/diabetes/pubs/estimates.htm#prev4).

Centers for Disease Control and Prevention. 2002. "Drug-Associated HIV Transmission Continues in the United States. Atlanta, GA: Centers for Disease Control and Prevention, Retrieved March 15, 2005. (http://www.cdc.gov/hiv/resources/factsheets/PDF/idu.pdf).

Centers for Disease Control and Prevention. 1999. "HIV and Its Transmission." Atlanta, GA: Centers for Disease Control and Prevention, Retrieved March 20, 2005. (http://www.cdc.gov/hiv/resources/factsheets/transmission.htm).

Centers for Disease Control and Prevention. 1981. "Pneumocycstis Pneumonia – Los Angeles." *Morbidity and Mortality Weekly Report* 30 (250-2): 1-2. Retrieved October 23, 2006. (http://www.cdc.gov/hiv/resources/reports/mmwr/pdf/mmwr05jun81.pdf).

Cerulo, Karen. 1997. "Identity Construction: New Issues, New Directions. *Annual Review of Sociology* 23: 385-409.

Chambre, Susan. 2006. *Fighting for Our Lives: New York's AIDS Community and the Politics of Disease*. Piscataway, NJ: Rutgers University Press.

Chambre, Susan M. 2001. "The Changing Nature of 'Faith' in Faith-Based Organizations: Secularization and Ecumenicism in Four AIDS Organizations in New York City." *Social Service Review* 75 (3): 435-455.

Chambre, Susan M. 1999. "Redundancy, Innovation and Fragmentation: HIV/AIDS Nonprofit Organizations in New York City, 1981-1992." *Policy Studies Journal* 27 (4): 840-854.

Chambre, Susan M. 1995. "Uncertainty, Diversity, and Change: The AIDS Community in New York City." Pp. 149-190 in *Research in Community Sociology*, edited by D. A. Chekki. Westport, CT: JAI Press.

Charmaz, Kathy. 2002. "Qualitative Interviewing and Grounded Theory Analysis." Pp. 675-694 in *Handbook of Interview Research: Context and Method*, edited by J.F. Gubrium and J.A. Holstein. Thousand Oaks, CA: Sage Publications.

Cohen, Cathy J. 1999. *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics.* Chicago, IL: The University of Chicago Press.

Cohen, Peter F. 1998. *Love and Anger : Essays on AIDS, Activism, and Politics*. Binghamton, NY: The Hayworth Press.

Cole, Kenneth. 2005. "Kenneth Cole Creates and Launches 'We All Have AIDS' Public Service Campaign on World AIDS Day." Press Release. *Yahoo! Financial News,* December 1. Retrieved December 22, 2005 (http://biz.yahoo.com/prnews/0512001/nyth025.html?.v=35&printer=1.htm).

Collins, Patricia Hill. 2004. *Black Sexual Politics: African Americans, Gender, and the New Racism.* New York, NY: Routledge.

Collins, Patricia Hill. 2000. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, 2nd ed. New York, NY: Routledge.

Cone, James H. 1996. *A Black Theology of Liberation*. Maryknoll, NY: Orbis Books.

Conrad, Peter. 1997. "The Social and Cultural Meanings of Illness." Pp. 106-109 in *The Sociology of Health and Illness: Critical Perspectives*, edited by P. Conrad. New York, NY: St. Martin's Press, Inc.

Conrad, Peter and Joseph W. Schneider. 1992. *Deviance and Medicalization: From Badness to Sickness.* Philadelphia, PA: Temple University Press.

Conrad, Peter. 1986. "The Social Meaning of AIDS." *Social Policy*, Summer: 51-56.

Cornell, Drucilla. 2000. *Just Cause: Freedom, Identity, and Rights*. Lanham, MD: Rowman and Littlefield.

Cohen, Cathy. 1996. "Contested Membership: Black Gay Identities and the Politics of AIDS." Pp. 362-394 in *Queer Theory/Sociology*, edited by S. Seidman. Cambridge, MA: Blackwell Publishers.

Constantine-Simms, Delroy. 2001. "Is Homosexuality the Greatest Taboo?" Pp.

76-87 in *The Greatest Taboo: Homosexuality in Black Communities*, edited by D. Constance-Simms. Los Angeles, CA: Alyson Books.

Cortese, Anthony J. 1999. *Provocateur: Images of Women and Minorities in Advertising.* Lanham, MD: Rowman & Littlefield Publishers, Inc.

Davis, Gerald F., Doug McAdam, W. Richard Scott, and Mayer N. Zald. 2005. *Social Movements and Organization Theory*. New York, NY: Cambridge University Press.

Dalton, Harlon L. 1989. "AIDS in Blackface." *Daedalus* 118(3): 205-227.

Douglas, Kelly Brown. 2003. *Sexuality and the Black Church: A Womanist Perspective*. Maryknoll, NY: Orbis Books.

Durkheim, Emile. 2001 (1912). *The Elementary Forms of Religious Life*. C. Cosman, trans. New York, NY: Oxford University Press.

Durkheim, Emile. 1982 (1895). *The Rules of the Sociological Methods*. Edited by S. Lukes. W.D. Halls, trans. New York, NY: Free Pres.

Durkheim, Emile. 1979 (1951). *Suicide: A Study in Sociology.* John A. Spaulding and George Simpson, trans. New York, NY: The Free Press.

Dunbar, Christopher Jr., Dalia Rodriguez, and Laurence Parker. 2002. "Race, Subjectivity, and the Interview Process." Pp. 279-298 in *Handbook of Interview Research: Context and Method*, edited by J.F. Gubrium and J.A. Holstein. Thousand Oaks, CA: Sage Publications.

DuBois, William Edward Burghardt. 1994 (1903). *The Souls of Black Folk*. Mineola, NY: Dover Publications, Inc.

Duneier, Mitchell. 2000. *Sidewalk*. New York, NY: Farrar, Straus and Giroux.

During, Simon. 1993. *The Cultural Studies Reader*. New York, NY: Routledge.

Dyson, Michael Eric. 2001. "When You Divide Body and Soul, Problems Multiply: The Black Church and Sex." Pp. 308-326 in *Traps: African American Men on Gender and Sexuality*, edited by R. P. Byrd and B. Guy-Sheftall. Bloomington, IN: Indiana University Press.

Edelman, J. Murray. 1977. *Political Language; Words that Succeed and Policies that Fail*. New York, NY: Academic Press.

Edgley, Charles and Dennis Brissett. 1999. *A Nation of Meddlers*. Boulder, CO: Westview Press.

Ehrenreich, Barbara and Deirdre English. 1973. *Witches, Midwives, and Nurses: A History of Women Healers*. New York, NY: The Feminist Press at The City University of New York.

Ellison, Christopher G. and Darren E. Sherkat. 1995. "The 'Semi-Involuntary Institution' –Revisited: Regional Variations in Church Participation Among Black Americans. *Social Forces* 73(4): 1415-1437.

Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley, CA: University of California Press.

Farber, Celia. 2006. "Out of Control: AIDS and the Corruption of Medical Science." *Harper's*, March, pp. 37-52.

Fausto-Sterling. 1999. "Menopause: The Calm Before the Storm." Pp. 169-178 in *Feminist Theory and the Body: A Reader*, edited by J. Price and M. Shildrick. New York, NY: Routledge.

Fears, Darryl. 2005. "Study: Many Blacks Cite AIDS Conspiracy: Prevention Efforts Hurt, Activists Say." *Washington Post* Tuesday, January 25: A02. Retrieved February 18, 2005. (http://www.washingtonpost.com/wp-dyn/articles/A33695-2005Jan24.html).

Fee, Elizabeth. 1988. "Sin Versus Science: Venereal Disease in Twentieth-Century Baltimore." Pp.121-143 in *AIDS: The Burdens of History,* edited by E. Fee and D.M. Fox. Berkeley, CA: University of California Press.

Fernando, Daniel M. 1993. *AIDS and Intravenous Drug Use The Influence of Morality, Politics, Social Science, and Race in the Making of a Tragedy*. Westport, CT: Praeger Publishers.

Fine, Seymour H. 1990. *Social Marketing: Promoting the Causes of Public and Nonprofit Agencies.* Boston, MA: Allyn and Bacon.

Ford, Chandra L. Kathryn D. Whetten, Susan Al. Hall, Jay S. Kaufman, and Angela D. Thrasher. 2007. "Black Sexuality, Social Construction, and Research Targeting 'The Down Low'" *Annals of Epidemiology*, 17(3): 209-216.

Formicola, Jo Renee, Mary C. Segers, and Paul Weber. 2003. *Faith-Based Initiatives and the Bush Administration: The Good, the Bad, and the Ugly.* Lanham, MD: Rowman & Littlefield Publishers, Inc.

Foucault, Michel. 1990 (1978). *The History of Sexuality: An Introduction, vol 1*. Robert Hurley, trans. New York, NY: Vintage Books.

Frazier, Franklin E. 1969 (1964). *The Negro Church in America.* New York, NY:

Schocken Books.

Franzini, Louis R. 1993. "The paradox of Accurate Information Increasing the Fear of AIDS. Pp. 71-90. Pp. 141-150 in *AIDS: Effective Health Communication for the 90s,* edited by S.C. Ratzan. Washington, DC: Taylor & Francis.

Freedman, Samuel G. 2006. "Muzzling Sex Education on Anything but Abstinence." *New York Times*, July 19. Retrieved July 20, 2006 (http://www.nytimes.com/2006/07/19/nyregion/19EDUCATION.html).

Freimuth, Vicki S., Sandra Crouse Quinn, Stephen B. Thomas, Galen Cole, Eric Zook, and Ted Duncan. 2001. "African Americans' Views on Research and the Tuskegee Syphilis Study." *Social Science and Medicine*, 52: 797-808.

Freudenberg, Nicholas, Marc A. Rogers, Cassandra Ritas, and sister Mary Nerney. 2005. "Policy Analysis and Advocacy: An Approach to Community-Based Participatory Research." Pp. 349-370 in *Methods in Community-Based Participatory Research for Health*, edited by B.A. Isreal, E. Eng, A.J. Schulz, and E.A. Parker. San Francisco, CA: Jossey-Bass, A Wiley Imprint.

Freund, Peter E.S. 1982. *The Civilized Body: Social Domination, Control, and Health.* Philadelphia, PA: Temple University Press.

Freund, Peter E.S. and Meredith B. McGuire. 1999. *Health, Illness, and the Social Body: A Critical Sociology*. Upper Saddle River, NJ: Prentice Hall.

Fullilove, Mindy Thompson and Robert E. Fullilove III. 1999. "Stigma as an Obstacle to AIDS Action." *American Behavioral Scientist* 42 (7): 1117-1130.

Fullilove, Mindy Thompson and Robert E. Fullilove III. 1997. "Homosexuality and the African American Church; The Paradox of the 'Open Closet.'" Pp. 1-14 in *Though I Stand at the Door and Knock: Discussions on the Black Church Struggle with Homosexuality and AIDS,* edited by The Balm in Gilead. New York, NY: The Balm in Gilead.

Futrell, Robert. 2004. "Framing Processes, Cognitive Liberation, and NIMBY Protest in the U.S. Chemical-Weapons Disposal Conflict." *Sociological Inquiry* 73(3): Page 359-386.

Gains, Kevin K. 1996. *Uplifting the Race: Black Leadership, Politics, and Culture in the Twentieth Century*. Chapel Hill, NC: The University of North Carolina Press.

Gamson, Joshua. 1996. "The Organizational Shaping of Collective Identity: The

Case of Lesbian and Gay Film Festivals in New York." *Sociological Forum* 11 (2): 231-261.

Gamson, Joshua. 1991. "Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement 'Newness.'" Pp. 35-57 in *Ethnography Unbound: Power and Resistance in the Modern Metropolis*, edited by M. Burawoy, A. Burton, A.A. Ferguson, K.J. Fox, J. Gamson, N. Gartrell, L. Hurst, C. Kurzman, L. Salzinger. J, Schiffman, and S. Ui. Berkley, CA: University of California Press.

Garfinkel, Harold. 1984. *Studies in Ethnomethodoloy*, 2nd edition. Cambridge, UK: Polity Press.

Gergen, Kenneth. 2003. "Knowledge as Socially Constructed." Pp. 15-18 in *Social Construction: A Reader*, edited by M. Gergen and K.J. Gergen. Thousand Oaks, CA: Sage Publications.

Gergen, Mary and Kenneth J. Gergen. 2003. "The Social Construction of the Real and the Good: Introduction." Pp. 2-7 in *Social Construction: A Reader*, edited by M. Gergen and K.J. Gergen. Thousand Oaks, CA: Sage Publications.

Gilbert, Dorie J. 2003. "Black Churches Respond to AIDS: Interview with Pernessa C. Seele, Founder and CEO of The Balm in Gilead." Pp. 153-158 in *African American Woman and HIV/AIDS: Critical Responses*, edited by D.J. Gilbert and E.M. Wright. Westport, CT: Praeger Publishers.

Gochros, Harvey L. 1988. "Risks of Abstinence: Sexual Decision Making in the AIDS Era." *Social Workers*, May-June: 254-256.

Goffman, Erving. 1976. *Gender Advertisements.* Cambridge, MA: Harvard University Press.

Goffman, Erving. 1974 (1986). *Frame Analysis: An Essay on the Organization of Experience*. Boston, MA: Northeastern University Press.

Goffman, Erving. 1986 (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York, NY: Simon and Schuster, Inc.

Goldstein, Richard. 1990. "The Implicated and the Immune: Cultural Responses to AIDS." *The Milbank Quarterly* 68(2/2): 295-319.

Gordon, Andrew J. 2000. "Cultural Identity and Illness: Fulani Views. *Culture, Medicine and Psychiatry* 24(3): 297-330.

Griffin, Horace. 2001. "Their Own Received Them Not: African American

Lesbians and Gays in Black Churches." Pp. 110-123 in *The Greatest Taboo: Homosexuality in Black Communities*, edited by D. Constance-Simms. Los Angeles, CA: Alyson Books.

Greene, Jennifer C. 1994. "Qualitative Program Evaluation." Pp. 530-544 in *Handbook of Qualitative Research*, edited by N.K. Denzin and Y.S. Lincoln. Thousand Oaks, CA: Sage Publications.

Glaser, Barney G. and Anselm L. Strauss. 1999 (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne, NY: Aldine de Gruyter.

Gorman, Christine. 2006. "Heroes and Pioneers." *Time*, May 8, pp. 88-99.

Good, Erich and Nachman Ben-Yehuda. 1994a. "Moral Panics: Culture, Politics, and Social Construction." *Annual Review of Sociology*, 20: 149-171.
Goode, Erich and Nachman Ben-Yehuda. 1994b. *Moral Panics: The Social Construction of Deviance.* Malden, MA: Blackwell Publishers, Inc.

Goodwin, Jeff and James M. Jasper. 2003. "Editor's Introduction." Pp.3-8 in *The Social Movements Readers: Cases and Concepts*, edited by J. Goodwin and J.M. Jasper. Malden, MA: Blackwell Publishing.

Greenberg, David F. 1990. *The Construction of Homosexuality.* Chicago, IL: The University of Chicago Press.

Griffin, Horace. 2001. "Their Own Received Them Not: African American Lesbians and Gays in the Black Church." Pp. 110-121 in *The Greatest Taboo: Homosexuality in Black Communities,* edited by D. Constantine-Simms. Los Angeles, CA: Alyson Books.

Gutman, Herbert G. 1976. *The Black Family in Slavery and Freedom: 1750-1925*. New York, NY: Vintage Books.

Haberlandt, M. (translated by B. Rose). 1998. "Occurrences of Contrary-Sex among in the Negro Population of Zanzibar (1899)." Pp. 63-66 in *Boy-Wives and Female Husbands: Studies of African Homosexualities,* edited by S.O. Murray and W. Roscoe. New York, NY: St. Martin's Press.

Harris, Leslie M. 2003. *In the Shadow of Slavery: African Americans in New York City 1626-1863.* Chicago, IL: The University of Chicago Press.

Hawkeswood, William G. 1996. *One of the Children: Gay Black Men in Harlem.* Berkeley, CA: University of California Press.

Hawthorne, Nathaniel. 1965 (originally published in 1850). *The Scarlet Letter.*

New York, NY: Bantam Books.

Herdt, Gilbert. 1992. "Introduction." Pp. 3-26 in *The Time of AIDS: Social Analysis, Theory, and Method*, edited by G. Herdt and S. Lindenbaum. Newbury Park, CA: Sage Publications.

Herdt, Gilbert and Shirley Lindenbaum. *The Time of AIDS: Social Analysis, Theory, and Method*. Newbury Park, CA: Sage Publications.

Herek, Gregory M. 1999. "AIDS and Stigma." *American Behavioral Scientists,* 42: 1106-1116.

Herek Gregory M. and Eric K. Glunt. 1997. "An Epidemic of Stigma: Public Reaction to AIDS." Pp. 125-132. In *The Sociology of Health and Illness: Critical Perspectives*, edited by P. Conrad. New York, NY: St. Martin's Press, Inc.

Herek, Gregory .M., & Glunt, Eric.K. 1988. An Epidemic of Stigma: Public Reactions to AIDS. *American Psychologist* 43 (11): 886-891.

Hernandez, Jeanne T., and Frank J. Smith. 1990. "Abstinence, protection, and Decision-Making: Experimental Trials on Prototypic AIDS Programs." *Health Education Research,* 5(2): 309-320.

HIV Epidemiology Program, New York City Department of Health and Human Hygiene. 2006. "New York City HIV/AIDS Annual Surveillance Statistics 2005." New York, NY: New York City Department of Health and Mental Hygiene, Retrieved January 9, 2007. (http://www.nyc.gov/html/doh/downloads/pdf/ah/surveillance2005_tables_all.pdf).

Hollingshead, August B. 1973. "Medical Sociology: A Brief Review." *Health and Society* 51(4): 531-542.

hooks, bell. 2001. "Homophobia in Black Communities." Pp. 67-75 in *The Greatest Taboo: Homosexuality in Black Communities*, edited by D. Constance-Simms. Los Angeles, CA: Alyson Books.

Howard, Thurman. 1989 (1965). *The Luminous Darkness: A Personal Interpretation of the Anatomy of Segregation and the Ground of Hope*. Richmond, IN: Friends United Press.

Hickman, Cynthia. 1999. *Harlem Churches at the End of the 20th Century*. New York, NY: Dunbar Press.

Jerolmack, Colin and Douglas Porpora. 2004. "Religion, Rationality, and

Experience: A Response to the New Rational Choice Theory of Religion." *Sociological Theory*, 22(1): 140-160.

Jonassen, Christen H. 1959. "Contributions of Sociology to Marketing." *Journal of Marketing* 24: 29-34.

Johnson, Cary Alan. 2001. "Hearing Voices: Unearthing Evidence of Homosexuality in Precolonial Africa." Pp. 132-148 in *The Greatest Taboo: Homosexuality in Black Communities,* edited by D. Constantine-Simms. Los Angeles, CA: Alyson Books.

Johnson, E. Patrick. 2001. "Feeling the Spirit in the Dark: Expanding Notions of the Sacred in the African American Gay Community." Pp. 88-109 in *The Greatest Taboo: Homosexuality in Black Communities*, edited by D. Constance-Simms. Los Angeles, CA: Alyson Books.

Johnston, Hank and Bert Klandermans (Eds). 1995. *Social Movements and Culture*. Minneapolis, MN: University of Minnesota Press.

Jones, Sue. 1985. "In-Depth Interviewing." Pp. 45-55 in *Applied Qualitative Research*, edited by R. Walker. Brookfield, VT: Gower Publishing Company.

Jumanne, Monifa A. 2005. "Black Church Leadership in the Age of AIDS: What Must We Do to Be Saved?" Pp. 146-152 in *Blow the Trumpet in Zion: Global Vision and Action for the 21st Century Black Church*, edited by I.E. Carruthers, F.D. Haynes III, and J.A. Wright Jr. Minneapolis, MN: Fortress Press.

Junker, Buford H. *Fieldwork: An Introduction to the Social Sciences*. Chicago, IL: The University of Chicago Press.

Katz Rothman, Barbara. 1982/1991. *In Labor: Women and Power in the Birthplace.* New York, NY: W.W. Norton and Company**.**

Kalb, Claudia and Andrew Murr. 2006. "Battling a Black Epidemic." *Newsweek*, May 15, pp. 43-48.

King, J.L. 2004. *On the Down Low: A Journey into the Lives of 'Straight' Black Men Who Sleep with Men* New York, NY: Broadway Books.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering and the Human Condition*. New York, NY: Basic Books.

Kleinman, Arthur. 1980. *Patients and Healers in the Context of Culture: An Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry.* Berkeley, CA: University of California Press.

K**NO**W HIV/AIDS. 2006. "Learn About the Campaign / About Us. K**NO**W HIV/AIDS, Retrieved March 19, 2006, (http://www.knowhivaids.org/learn_about.html).

Kolker, Emily S. 2005. "Framing as a Cultural Resource in Health Social Movements: Funding Activism and the Breast Cancer Movement in the US 1990-1996." Pp. 137-160 in *Social Movements in Health*, edited by P. Brown and S. Zavestoski. Malden, MA: Blackwell Publishing.

Kornblum, William. 1996. "Introduction." Pp. 1-7 in *Readings on the Field Research Experience*, edited by Carolyn D. Smith and William Kornblum. Westport, CT: Praeger.

Kotler, Philip and Alan R. Andreasen. 1996. *Strategic Marketing for Non-Profit Organizations*, 5th edition. Upper Saddle River, NJ: Prentice Hall, Inc.

Kotler, Philip and Eduardo L. Roberto. 1989. *Social Marketing: Strategies for Changing Public Behavior.* New York, NY: The Free Press.

Kotler, Philip, Ned Roberto, and Nancy. 2002. *Social Marketing: Improving the Quality of Life.* Thousand Oaks, CA; Sage Publications.

Kramer, Roderick M. 2001. "Identity and Trust in Organizations: One Anatomy of a Productive but Problematic Relationship. M.A. Hogg and D.J. Terry (Eds). Pp. 167-180 in *Social Identity Processes in Organizational Contexts.* Psychology Press, Taylor and Francis Group: Philadelphia, PA.

Krippendorff, Klaus. 2003. *Content Analysis: An Introduction to Its Methodology*. Thousand Oaks, CA: Sage Publications.

Krause, Neal, Christopher G. Ellison, and Jack P. Marcum. "The Effects of Church-Based Emotional Support on Health: Do They Vary by Gender." *Sociology of Religion* 63 (1): 21-47.

Kuo, David. 2006. *Tempting Faith: An Inside Story of Political Seduction*. New York, NY: Free Press.

LA Gay and Lesbian Center. 2006. "LA Gay and Lesbian Center Launches Bold HIV/AIDS Awareness Campaign." Los Angeles, CA: LA Gay and Lesbian Community Center, Retrieved January 11, 2007 (http://www.lagaycenter.org/site/c.mvI4IhNZJwE/b.1070409/apps/s/content.asp?ct=2944265).

Lane, Jeremy F. 2000. *Pierre Bourdieu: A Critical Introduction*. London, UK: Pluto Press.

Langone, John. 1988. *AIDS: The Facts*. Boston, MA: Little, Brown and Company.

Larana, Enrique, Hank Johnston, and Joseph R. Gusfield. *New Social Movements: From Ideology to Identity*. Philadelphia, PA: Temple University Press.

Lawrence-Lightfoot, Sara. 1995. *Balm in Gilead: Journey of a Healer.* New York, NY: Penguin Books.

Leary, Mark R. and Lisa S. Schreindorfer. 1998. "The Stigmatization of HIV and AIDS: Rubbing Salt in the Wound." Pp. 12-29 in *HIV and Social Interaction*, edited by V.J. Derlega and A.P. Barbee. Thousand Oaks, California: Sage.

Lemann, Nicholas. 1992. *The Promised Land: The Great Black Migration and How It Changed America*. New York, NY: Vintage Books.

Levenson, Jacob. 2004. *The Secret Epidemic: The Story of AIDS and Black America.* New York, NY: Pantheon Books.

Lewis, Jacqueline. 1999. "Status Passages: The Experiences of HIV-Positive Gay Men." *Journal of Homosexuality* 1999 37(3): 87-115.

Liebow, Elliot. 1968. *Tally's Corner*. Boston, MA: Back Bay Books.

Lincoln, Eric C. and Lawrence H. Mamiya. 1990. *The Black Church in the African American Experience.* New York, NY: Duke University Press.

Lindenbaum, Shirley. 1998. "Images of Catastrophe: The Making of an Epidemic." Pp. 33-59 in *The Political Economy of AIDS*, edited by M. Singer. Amityville, NY: Baywood Publishing Company, Inc.

Linton, Simi. 1998. *Claiming Disability: Knowledge and Identity.* New York, NY: New York University Press.

Lorber, Judith. 1997. *Gender and the Social Construction of Illness*. Thousand Oaks, CA: Sage Publications, Inc.

Lorde, Audre. 1984 (1992). *Sister Outsider: Essays and Speeches by Audre Lorde.* Freedom, CA: The Crossing Press.

Lorde, Audre. 1980. *The Cancer Journals.* San Francisco, CA: Aunte Lute Books.

Lupton, Deborah. 2000. *Medicine as Culture: Illness, Disease and the Body in Western Societies*. Thousand Oaks, CA: Sage Publications, Inc.

Lupton, Deborah. 1997. *The Imperative of Health: Public Health and the Regulated Body*. Thousand Oaks, CA: Sage Publications, Inc.

Lupton, Deborah. 1994. *Moral Threats and Dangerous Desires: AIDS in the News Media*. Bristol, PA: Taylor & Francis.

Mannheim, Karl. 1936 (1985). *Ideology and Utopia: An Introduction to the Sociology of Knowledge*. Orlando, FL: Harcourt, Inc.

March of Dimes. 2007. "About Us." White Plains, NY: March of Dimes, Retrieved January 11, 2007. (http://www.marchofdimes.com/aboutus/789_821.asp).

Markus, Hazel, and Nurius, Paula. 1986. "Possible Selves." *American Psychologist*, 41(19): 954-969.

Martin, Emily. 1999. "The Egg and the Sperm: How Science has Constructed a Romance Based on Stereotypical Male-Female Roles." Pp. 179-189 in *Feminist Theory and the Body: A Reader*, edited by J. Price and M. Shildrick. New York, NY: Routledge.

Martin, Emily. 1994. *Flexible Bodies: Tracking Immunity in American Culture – From the Days of Polio to the Age of AIDS.* Boston, MA: Beacon Press.

Martin, Emily. 1987. *The Woman in the Body: A Cultural Analysis of Reproduction*. Boston, MA: Beacon Press.

Marx, Karl. 1867 (1978). "Capital, Volume One." Pp. 294-438 in *The Marx – Engels Reader,* the second edition, edited by R. C. Tucker. New York, NY: W.W. Norton & Company, Inc.

McAllister, Matthew P. 1993. "AIDS, Medicalization, and the News Media." Pp. 195-221 in *AIDS: A Communication Perspective*, edited by T. Edgar, M.A. Fitzpatrick, and V.S. Freimuth. Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.

McAdam, D. and W. Richard Scott. 2005. "Organizations and Movements." Pp. 4-41 in *Social Movements and Organization Theory*, edited by G.F. Davis, D. McAdam, W.R. Scott, and M.N. Zald. New York, NY: Cambridge University Press. McBride, Dwight. 2005. *Why I Hate Abercrombie and Fitch*. New York, NY: New York University Press.

McKnight, Erica L. 2005. "Restoring Our Faith: HIV/AIDS and Black Faith Communities: An Interview with Pernessa Seele. *Harvard Journal of African American Public Policy* 11: 71-77.

McQuiston, Chris, Emilio A. Parrado, Julio Ceasar Olmos-Muniz, and Alejandro M. Bustillo Martinez. 2005. "Community-Based Participatory Research and Ethnography." Pp. 210-229 in *Methods in Community-Based Participatory Research for Health*, edited by B.A. Isreal, E.Eng, A.J. Schulz, and E.A. Parker. San Francisco, CA: Jossey-Bass, A Wiley Imprint.

Merton, Robert K. 1973. "Social and Cultural Context of Science." Pp. 173-190, in *The Sociology of Science: Theoretical and Empirical Investigations*, edited by N.W. Storer. Chicago, IL: The University of Chicago Press.

Merton, Robert K. 1962a. "Priorities in Scientific Discovery: A Chapter in the Sociology of Science. 447-485 in *The Sociology of Science*, edited by B. Barber and W. Hirsch. New York, NY: The Free Press of Glencoe.

Merton, Robert K. 1962b. "Science and the Social Order." Pp. 16-33 in *The Sociology of Science*, edited by B. Barber and W. Hirsch. New York, NY: The Free Press of Glencoe.

Mitchell, Henry H. 2004. *Black Church Beginnings: The Long-Hidden Realities of the First Years*. Grand Rapids, MI: William B. Eerdman's Publishing Company.

Mullings, Leith. 2003. "After Drugs and the 'War on Drugs': Reclaiming the Power to Make History in Harlem, New York." Pp. 173-199 in *Wounded Cities: Destruction and Reconstruction in a Globilized World*, edited by J. Schneider and I. Susser. New York, NY: Berg.

Murray, Stephen O. and Will Roscoe. 1998. *Boy-Wives and Female Husbands: Studies of African Homosexualities*. New York, NY: St. Martin's Press.

National Center for HIV, STD, and TB Prevention. 2004. "The Tuskegee Syphilis Study: A Hard Lesson Learned." Atlanta, Georgia: Centers for Disease Control and Prevention. Retrieved December 5, 2004. (http://www.cdc.gov/nchstp/od/tuskegee/time.htm).

Neuendorf, Kimberley A. 2002. *The Content Analysis Guidebook*. Thousand Oaks, CA: Sage Publications.

Newman, Susan. 2002. *Oh God! : A Black Woman's Guide to Sex and Spirituality.* New York, NY: The Ballantine Publishing Group.

Nisbet, Robert. 1971. "Introduction: The Study of Social Problems." Pp 1-28 in *Contemporary Social Problems*, edited b R. Merton and R. Nisbet. Re York, NY: Harcourt Brace Javonovich.

Null, Gary and James Feast. 2002. *AIDS: A Second Opinion.* New York, NY: Seven Stories Press.

Office of Minority Health. 2006. "Eliminate Disparities in Infant Mortality." Atlanta, GA: Centers for Disease Control and Prevention. Retrieved September 29, 2006. (http://www.cdc.gov/omh/AMH/factsheets/infant.htm).

Ogden, Lydia, Melissa Shepherd, William A. Smith, and Porter/Novelli, 1996. *The Prevention Marketing Initiative: Applying Prevention Marketing.* Atlanta, GA: The Centers for Disease Control and Prevention.

Olien, Clarice .N., Phillip J. Tichenor, and George A Donohue. 1989. "Media Coverage and Social Movements." Pp. 139-163 in *Information Campaigns: Balancing Social Values and Social Change*, edited by C.T. Salmon. Newbury Park, CA: Sage Publications.

Oppenheimer, Gerald M. 1992. "Causes, Cases, and Cohorts: The Role of Epidemiology in the Historical Construction of AIDS." Pp. 49-83 in *AIDS: The Making of a Chronic Disease*, edited by E. Fee and D.M. Fox. Berkeley, CA: University of California Press.

Oyserman, Daphna and Hazel Markus. 1990. "Possible Selves in Balance: Implications for Delinquency. *Journal of Social Issues,* 46(2): 141-157.

Oyserman, Daphna and Hazel R. Markus. 1990. "Possible Selves and Delinquency." *Journal of Personality and Social Psychology*, 59(1): 112-125.

Paris, Peter J. 1985. *The Social Teaching of the Black Churches*. Philadelphia, PA: Fortress Press.

Parsons, Talcott. 1964 (1951). *The Social System.* New York, NY: The Free Press of Glencoe.

Parsons, Talcott. 1962. "The Institutionalization of Scientific Investigation." Pp 7-15 in *The Sociology of Science*, edited by B. Barber and W. Hirsch. New York, NY: The Free Press of Glencoe.

Patillo-McCoy, Mary. 2000. *Black Picket Fences: Privilege and Peril Among the Black Middle Class*. Chicago, IL: The University of Chicago Press.

Pattillo-McCoy. 1998. "Church Culture as a Strategy of Action in the Black Community." *American Sociological Review* 63(6): 767-784.

Patton, Cindy. 1990. *Inventing AIDS.* New York, NY: Routledge, Chapman, and Hall, Inc.

Peitzman, Steven J. 1992. "From Bright's Disease to End-Stage Renal Disease." Pp. 3-19 in *Framing Disease: Studies in Cultural History*, edited by C.E. Rosenberg and J. Golden. New Brunswick, NJ: Rutgers University Press.

Peterson, Jane, Jan R. Atwood, and Bernice Yates. 2002. "Key Elements for Church-Based Health Promotion Programs: Outcome-Based Literature Review." *Public Health Nursing* 19(6): 401-411.

Pike, Elizabeth C.J. 2002. "Injury, Illness and Sporting Identity: A Symbolic Interactionist Perspective. Paper presented at the annual meeting of the I nternational Sociological Association, Brisband, Australia.

Pinn, Anne H. and Anthony B. Pinn. 2002. *Fortress Introduction to Black Church History*. Minneapolis, MN: Fortress Press.

Pitts, Jesse 1968. "Social Control: The Concept. Pp. 395 in *International Encyclopedia of Social Sciences* (Vol. 14), edited by D. Sills. New York, NY: Macmillan Publishing Co

Poe, Edgar Allan. 1992 (1843). "The Masque of the Red Death" in *The Complete Tales and Poems of Edgar Allan Poe.* New York, NY: Barnes and Nobles.

Polletta, Francesca and James M. Jasper. 2001. "Collective Identity and Social Movements." *Annual Review of Sociology* 27: 283-305.

Porter, Roy. 2003. *Blood and Gust: A Short History of Medicine.* New York, NY: W.W. Norton and Company.

POZ. 2004. "Magic Johnson: Man of the Year." *POZ*, May, pp. 59.

Quandt, Sara A., Juliana McDonald, Rony A. Bell, and Thomas A. Arcury. 1999. "Aging Research in Multi-Ethnic Rural Communities: Gaining Entrée Through Community Involvement. *Journal of Cross-Cultural Gerontology* 14: 113-130.

Quimby, Ernest and Samuel R. Friedman. 2003. "Dynamics of Black Mobilization Against AIDS in New York City." Pp. 145-159 in *Health and Health Care Social Problems*, edited by P. Conrad and V. Leiter. Lanham, MD: Rowman and Littlefield Publishers, Inc.

Quinn, Sandra Crouse. 1993. "Reducing AIDS Through Community Education (RACE): Evaluating a Church-Based AIDS Education Program for Black Americans." Ph.D. dissertation, University of Maryland, College Park, College Park, MD.

Raboteau, Albert J. 2001. *Canaan Land: A Religious History of African Americans*. New York, NY: Oxford University Press.

Riggs, Marlon. 2001. "Black Macho revisited: Reflections of a SNAP! Queen." Pp.

292-296 in *Traps: African American Men on Gender and Sexuality*, edited by R.P. Byrd and B.Guy-Sheftall. Bloomington, IN: Indiana University Press.

Rosenberg, Charles E. 1989. "Disease in History: Frames and Framers." *The Milbank Quarterly*, 67(1): 1-15.

Schiebinger, Londa. 1999. "Theories of Gender and Race." Pp. 21-31 in *Feminist Theory and the Body: A Reader*, edited by J. Price and M. Shildrick. New York, NY: Routledge.

Sernett, Milton. 1999. *African American Religious History: A Documentary Witness, 2nd Edition.* Durham, NC: Duke University Press.

Seidman, Irving. 1998. *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences*. New York, NY: Teachers College press.

Sharrock, Cath. 1997. "Pathologizing Sexual Bodies." In *Lesbian and Gay Studies: A Critical Introduction*. Pp. 356-368, edited by A. Medhurst and S.R. Munt. London, UK: Cassell Academic.

Shilts, Randy. 1987. *And the Band Played on.* New York, NY: Penguin Group.

Singer, Merrill. 1989. "Forging a Political Economy of AIDS." Pp. 3-30 in *The Political Economy of AIDS*, edited by M. Singer. Amityville, NY: Baywood Publishing Company, Inc.

Sontag, Susan. 1989. *AIDS and Its Metaphors.* Toronto, Ontario: Collins Publishers Shelp, Earl E. and Ronald H. Sunderland. 1992. *AIDS and the Church: The Second Decade.* Louisville, KY: Westminster/John Knox Press.

Smith, Barbara and Beverly Smith. 1983. "Across the Kitchen Table: A Sister-to-Sister Dialogue." Pp. 113-127, in *This Bridge Called My Back: Writings By Radical Women of Color*, edited by C. Moraga and G. Anzaldua. New York, NY: Kitchen Table: Women of Color Press.

Snow, David A., E. Burke Rochford Jr, Steven K. Worden, and Robert D. Benford. 1986. "Frame Alignment Processes, Micromobilization and Movement Participation." *American Sociological Review* 51: 464-81.

Somerville, Siobhan B. 2000. *Queering the Color Line: Race and the Invention of Homosexuality in American Culture*. Durham, NC: Duke University Press.

Spector, Malcolm and John I. Kitsuse. 1987. *Constructing Social Problems.* Hawthorne, NY: Aldine de Gruyter.

Starkman, Naomi and Nicole Rajani. 2002. "The Case for Comprehensive Sex

Education." *AIDS Patient Care and STDs*, 16(7): 313-318.

Starr, Paul. 1982. *The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry*. New York, NY: Basic Books.

Starkman, Naomi and Nicole Rajani. 2002. "The Case for Comprehensive Sex Education." *AIDS Patient Care and STD* 16(7): 313-318.

Stinchcombe, Arthur L. 1987 (1968). *Constructing Social Theories*. Chicago, IL: The University of Chicago Press.

Stoller, Nancy E. 1998. *Lessons from the Damned: Queers, Whores, and Junkies Respond to AIDS.* New York, NY: Routledge.

Surveillance Epidemiology and End Results. 2004a. "Age-Adjusted SEER Incidence and U.S. Death Rates and 5-Year Relative Survival Rates." Bethesda, MD: National Cancer Institute, Retrieved September 28,2006 (http://seer.cancer.gov/csr/1975_2003/results_single/sect_01_table.06_2pgs.pdf).

Surveillance Epidemiology and End Results. 2004b. "Age-Adjusted U.S Death Rates and Trends for the Top 15 Cancer Sites by Race/Ethnicity." Bethesda, MD: National Cancer Institute, Retrieved September 28, 2006 (http://seer.cancer.gov/csr/1975_2003/results_merged/topic_mor_trends.pdf).

Surveillance Epidemiology and End Results. 2004c. "SEER Incidence and U.S. Mortality Trends by Primary Cancer Site and Sex." Bethesda, MD: National Cancer Institute, Retrieved September 28, 2006 (http://seer.cancer.gov/csr/1975_2003/results_single/sect_01_table.09_2pgs.pdf).

Swain, Kristie Alley. 1999. "Barriers and Inroads to AIDS Dialogue in the African-American Church; Development of a Strategic Model and Tool for Network Diffusion of Abstinence-Based HIV Prevention Advice." Ph.D. dissertation, College of Journalism and Communication, University of Florida, Gainesville, FL.

Swartz, David. 1997. *Culture and Power: The Sociology of Pierre Bourdieu*. Chicago, IL: The University of Chicago Press.

Swidler, Ann. 1986. "Culture in Action: Symbols and Strategies." *American Sociological Review* 51(2): 273-286.

Tarrow, Sidney. 1998. *Power in Movement: Social Movements and Contentious Politics*, 2nd edition. New York, NY: Cambridge University Press.

Taylor, Susan L. 2005. "Thirty-Five of Our Most Beautiful Women." *Essence*

Magazine, May 2005, pp. 198-231.eek

Tewkesbury, Richard. 1994. " 'Speaking of Someone with AIDS…': Identity Constructions of Persons with HIV Disease." *Deviant Behavior* 15(4): 337-355.

Tewksbury, Richard and Deana McGaughey. 1998. "Identities and Identity Transformation Among Persons with HIV Disease." *Journal of Gay, Lesbian, and Bisexual Identity* 3(3): 213-232.

Thomas, Stephen B. and Sandra Crouse Quinn. 1991. "The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community. *America Journal of Public Health*, 81: 1498-1505.

Thompson, Kenneth. 1998. *Moral Panics*. New York, NY: Routledge.

Tilly, Charles. 2004. *Social Movements, 1789-2004*. Boulder, CO: Paradigm Publishers.

Treichler, Paula A. 1999. *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham, NC: Duke University Press.

Treichler, Paula. 1992. "AIDS, HIV, and the Cultural Constructions of Reality." Pp. 65-98 in *The Time of AIDS: Social Analysis, Theory, and Method*, edited by G. Herdt and S. Lindenbaum. Newbury Park, CA: Sage Publications, Inc.

Turner, Bryan S. 1997. "From Governmentality to Risk: Some Reflections on Foucault's Contribution to Medical Sociology. Pp. ix-xxi in *Foucault: Health and Medicine,* edited by A. Petersen and R. Bunton. New York, NY: Routledge.

U.S. Census Bureau. 2006. "Race, Combinations of Two Races, and Not Hispanic or Latino: 2000." Washington, DC: U.S. Census, Retrieved September 28, 2006 (http://factfinder.census.gov/servlet/QTTable?_bm=y&-geo_id=01000US&-qr_name=DEC_2000_SF1_U_QTP4&-ds_name=DEC_2000_SF1_U).

Van Vugt, Johannes P. 1994. "The Effectiveness of Community-based Organizations in the Medical Social Sciences: A Case Study of a Gay Community's response to the AIDS Crisis." Pp. 13-34 in *AIDS Prevention and Services: Community-based Research,* edited by J.P. Van Vugt. Westport, CT: Bergin Garvey.

Washington, Harriet A. 2006. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from the Colonial Times to the Present.* New York, NY: Doubleday.

We All Have AIDS If One of Us Does. 2006. "The Mission." Retrieved February

9, 2006. (http://weallhaveaids.com/mission/default.asp).

Weatherford, Ronald Jeffrey and Carole Boston Weatherford. 1999. *Somebody's Knocking at Your Door: AIDS and the African-American Church."* New York, NY: The Haworth Pastoral Press.

Weber, Max. 2002 (1905). *The Protestant Ethic and The Spirit of Capitalism*. Stephen Kalberg, trans. Los Angeles, CA: Roxbury Publishing Company.

Weber, Max. 1958. "Politics as a Vocation." Pp. 77-128 in *From Max Weber: Essays in Sociology*, edited by H.H. Gerth and C. Wright Mills. New York, NY: Oxford University Press.

Weinreich, Nedra Kline. 1999. *Hands-On Social Marketing: A Step by Step Guide.* Thousand Oaks, CA: Sage publications.

Weitz, Rose. 1991. *Life with AIDS.* New Brunswick, NJ: Rutgers University Press.

West, Cornel. 1997. "The Black Church Beyond Homophobia." Pp.15-22 in *Though I Stand at the Door and Knock: Discussions on the Black Church Struggle with Homosexuality and AIDS,* edited by The Balm in Gilead. New York, NY: The Balm in Gilead.

Whyte, William Foote. 1993 (1943). *Street Corner Society: The Social Structure of an Italian Slum*. Chicago, IL: The University of Chicago Press.

West, Cornel. 2001. "Black Sexuality: The Taboo Subject." Pp. 301-307 in in *Traps: African American Men on Gender and Sexuality*, edited by R. P. Byrd and B. Guy-Sheftall. Bloomington, IN: Indiana University Press.

White, John Frank. 2003. "The Impact of the Black Church on the HIV/AIDS Epidemic in the Black Communities of Broward and Miami-Dade Counties." Ed.D. dissertation, Department of Education, Nova Southeastern University, Fort Lauderdale-Davie, FL.

Williams, Juan. 1987. *Eyes on the Prize: American's Civil Rights Years 1954-1965*. New York, NY: Penguin Publishers.

Williams, Juan and Quinton Dixie. 2003. *This Far by Faith: Stories from the African American Religious Experience*. New York, NY: HarperCollins Publishers.

Williams, Rhys H. 1995. "Constructing the Public Good: Social Movements and Cultural Resources." *Social Problems* 42(1): 124-144.

Wilmore, Gayraund S. 2004. *Black Religion and Black Radicalism: An*

Interpretation of the Religious History of African Americans. Maryknoll, NY: Orbis Books.

Wilson, Linette C. 2000. "Implementation and Evaluation of Church-Based Health Fairs." *Journal of Community Health Nursing* 17 (1): 39-48.

Wimberly, Edward P. 1979. *Pastoral Care in the Black Church.* Nashville, TN: Abingdon.

Wise, Janet Marie Bell. 1997. "Changing Clergy and Lay Leader Attitudes About HIV/AIDS: The Effectiveness of AIDS Education." Ed.D. dissertation, Department of Education, North Carolina State University, Raleigh, NC.

Wolfe, Maxine. 1994. "The AIDS Coalition to Unleash Power (ACT UP): A Direct Model of Community Research for AIDS Prevention. Pp. 216-247 in *AIDS Prevention and Services: Community-based Research,* edited by J.P. Van Vugt. Westport, CT: Bergin Garvey.

Wright, Kai and Zulaika Jamaralli. 2005. "Pulse: The Top 5 HIV Myths." *Essence* December. Retrieved March 20, 2006. (http://www.balmingilead.org/press/press_archives/2005/press_1205_5myths_essence.asp).

Yin, Robert K. 2003a. *Applications of Case Study Research*. Thousand Oaks, CA: Sage Publications.

Yin, Robert K. 2003b. *Case Study Research: Design and Methods*. Thousand Oaks, CA: Sage Publications.