Names Project Aids Memorial Quilt: A rhetorical study of the transformation of an epidemic through social movement

Daniel C Hinkley

University of Nevada, Las Vegas

Follow this and additional works at: https://digitalscholarship.unlv.edu/rtds

Repository Citation
https://digitalscholarship.unlv.edu/rtds/1551

This Thesis is brought to you for free and open access by Digital Scholarship@UNLV. It has been accepted for inclusion in UNLV Retrospective Theses & Dissertations by an authorized administrator of Digital Scholarship@UNLV. For more information, please contact digitalscholarship@unlv.edu.
NAMES PROJECT AIDS MEMORIAL QUILT:
A Rhetorical Study of the Transformation of an Epidemic Through Social Movement

by

Daniel Hinkley

Master of Arts
University of Nevada, Las Vegas
2003

A thesis submitted in partial fulfillment of the requirements for the

Master of Arts Degree in Communication Studies
Hank Greenspun School of Communication
Greenspun College of Urban Affairs

Graduate College
University of Nevada, Las Vegas
May 2003
Thesis Approval
The Graduate College
University of Nevada, Las Vegas

April 4, 2003

The Thesis prepared by

Daniel C. Hinkley

Entitled
Names Project AIDS Memorial Quilt:
A Rhetorical Study of the Transformation
of an Epidemic through Social Movement

is approved in partial fulfillment of the requirements for the degree of

MASTER OF ARTS COMMUNICATION

Richard J. Ferrer
Examination Committee Chair

Dean of the Graduate College

Examination Committee Member

Examination Committee Member

Graduate College Faculty Representative
ABSTRACT

Names Project AIDS Memorial Quilt: A Rhetorical Study of the Transformation of an Epidemic through Social Movement

by

Daniel Hinkley

Dr. Richard Jensen, Examination Committee Chair
Professor of Communication
University of Nevada, Las Vegas

This study looks at the Names Project: AIDS Memorial Quilt as a rhetorical artifact and centerpiece of the current AIDS movement. The methodology for this study is an ethnographic and auto-ethnographic design, utilizing interviews with four Quilt volunteers and staffers, including my observations as a person living with AIDS. This study looks at the Quilt using social movement, rhetorical, and dramatist theories to prove that the Quilt is the rhetorical centerpiece of the AIDS Movement. Social movement theories explain how the Quilt mobilized thousands of people to fight AIDS. Rhetorical theories explain how the Quilt transformed the belief that AIDS was just killing “gay perverts” to an honest understanding that AIDS does not discriminate. Dramatist theories explain the emotionalism at work within the Quilt. Finally this study looks at the future use of the Quilt as an information tool to be used in the prevention of the spread of AIDS.
ACKNOWLEDGEMENTS

When I began my masters program at UNLV, my determination was to just get through a course or two to see if I was up the task of being a mature graduate student. After several classes this thesis was born and it has proved to be a labor of love and commitment to new tomorrows that look different than my yesterdays.

To complete this thesis took many hours of research and study of the contributions of many communication scholars and this study could not have been completed without their scholarly offerings. I would also like to express my appreciation for the contributions of my interviewed subjects who graciously gave their time for this study. Especially I would like to acknowledge Cleve Jones, the AIDS Quilt founder, for without his early activism and recognition of the need for a special communication tool that turned out to be the Names Project AIDS Quilt, this study would not have been possible. I would like to thank my communications professors who supported my study unconditionally. Professors Jensen, Ferri, Chapel, Engstrom, Dillman, Traudt, and Halstuk all provided a scholarly classroom environment that fostered many hours of learning.

Professor Richard Jensen, my thesis committee chair has contributed much while overseeing this study through multiple gab sessions, edits, and rewrites and I could not have completed this study without his support. And I would like to thank my thesis committee, Professors Jensen, Ferri, Mullin, and Langston for waiting an additional year for this study to be completed.
And finally, I would like to acknowledge my life partner Ronald Lawrence, without whose inspiration this study could not have been completed. From the beginning he has offered encouragement and support that has been instrumental to my completion of my masters program and this thesis.

Thank you to all.
TABLE OF CONTENTS

ABSTRACT .................................................................................................................................. iii

ACKNOWLEDGEMENTS ........................................................................................................ iv

CHAPTER 1  INTRODUCTION ............................................................................................... 1
  Purpose ...................................................................................................................................... 3
  Justification .............................................................................................................................. 4
  Review of Literature ............................................................................................................... 7
  Methodology .......................................................................................................................... 11

CHAPTER 2  THE AIDS QUILT GOES TO WASHINGTON ......................................... 17
  Movement Theory .................................................................................................................. 17
  Rhetorical Theory .................................................................................................................. 24
  Dramatist Theory ................................................................................................................... 31

CHAPTER 3  HOMOPHOBIA AND AIDS IN THE 80’s .................................................. 41
  Fighting for Equality! ........................................................................................................... 43
  Late Out Of The Gate? ......................................................................................................... 53
  Help Yourself or Die! ............................................................................................................ 54
  Politics and Public Health! ................................................................................................... 57
  What to Fear: Sec or Homosexuals? .................................................................................. 60
  What Did We Learn? ............................................................................................................ 62

CHAPTER 4  AIDS – MY COMMUNITY – AND ME ..................................................... 65
  My Community ..................................................................................................................... 69
  Cleve Jones – Names Project Founder .............................................................................. 70
  Kay Valerdo – Las Vegas Names Project Chapter Organizer ............................................. 75
  Gert McMullin – Names Project Production Co-ordinator ............................................... 80
  Matt Kaminski – Names Project Office Receptionist ......................................................... 83
  Dan Hinkley – Person with AIDS – Personal Memoirs ..................................................... 85

CHAPTER 5  SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS ............ 92

APPENDIX I ............................................................................................................................ 102
  Interview Questions ............................................................................................................ 102

BIBLIOGRAPHY ...................................................................................................................... 104

VITA ............................................................................................................................................ 107

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
CHAPTER 1

INTRODUCTION

November 1985 - The headline in the San Francisco Chronicle read, “1,000 San Franciscans Dead of AIDS.” AIDS was silently sweeping the country, causing untold heartbreak and horror to the gay community. Cleve Jones, a San Francisco gay activist understood the predicament facing the gay community as it struggled to cope during this epidemic. He knew that no one was grasping the gravity of what was happening because there was no “visual instrument” to assist the greater community to understand the loss that was happening in the Castro, the predominately gay neighborhood in San Francisco. The need for this “visual instrument” was not lost on Jones as he angrily said during a conversation with his friend Joseph, “I wish we had a bulldozer, and if we could just level these buildings, raze Castro...if this was just a graveyard with a thousand corpses lying in the sun, then people would look at it and they would understand and if they were human beings they’d have to respond”(Jones & Dawson 105). During this memorial, a windstorm came up and many of the placards were dislodged from the side of the building and became scattered all about. In this scene Jones says he:

saw a quilt and was flooded with memories of home and family and the warmth of a quilt when it was cold on a winter night. As I scanned the patchwork, I saw it – as if a Technicolor slide had fallen into place. Where before there had been a flaking gray wall, now there was a vivid picture and I could see quite clearly the national mall, and the dome of Congress and a quilt spread out before it – a vision of incredible clarity. (Jones & Dawson 107)
This thesis will answer the question as to whether a social movement was born that day along with the vision of the Quilt. I believe so and therefore I agree that this event was the genesis of a social movement within the AIDS movement, that would take the form of an AIDS memorial dedicated to the celebration of the lives of those who had died of this terrible disease. The “visual instrument” Jones saw in his head would become the Names Project AIDS Memorial Quilt – the rhetorical centerpiece of the AIDS movement and it would help transform the hopeless reality the community faced during this AIDS crisis into a scenario where allies could be found and battles could be fought that would begin to restore dignity to those who had lost their lives to the AIDS virus.

Further evidence I will offer in this paper suggests that this redefinition took place and it took place because of the rhetorical qualities of the AIDS Quilt. Further, I will explore what this ultimately meant to the social fabric of America when the government began to feel the force of an AIDS oriented social movement. When AIDS went “mainstream,” funding opened up for research for drugs to combat the AIDS virus. Social needs of people with AIDS began to be addressed when AIDS was no longer seen as a disease only affecting gay men, drug addicts, or Haitians. These changes were not entirely caused by the AIDS Quilt but I believe the Quilt played a significant part in increased social services for people with AIDS (PWAs) and I will explore this aspect to see what I can find that would suggest a “cause and effect” relationship. Anecdotally, I know that the Ryan White Care Act was passed into law and signed by President Bush in 1990, three years after the Names Project AIDS Quilt began annual exhibits in Washington, D.C.
This thesis is organized into five chapters: the introductory chapter will outline the purpose, justification, review of literature, and methodology; the second chapter, the “Quilt as Social Movement” will discuss three theories, movement, rhetorical and dramatistic to provide explanation for how the AIDS Quilt was able to do its work as the rhetorical centerpiece of the AIDS movement; the third chapter, “Homophobia and AIDS in the 80’s” discusses homophobia and how that phenomena created the societal need for the AIDS quilt to fight against the indifference that impacted the AIDS epidemic; the fourth chapter is a combined personal memoirs and interviews chapter that will provide insights into how AIDS affected the gay community and how the AIDS Quilt impacted America’s response to the AIDS epidemic; and lastly a concluding chapter will summarize the findings of the thesis, discuss the importance of the findings, and propose future avenues of research. Using this organizational scheme, it is my intention to tell a story about AIDS and the Names Project Quilt. To do this, I will use social movement theories to offer an explanation why the Names Quilt was created and further why it has been successful as an organizing tool.

Purpose

This study will investigate the AIDS Quilt as a communication artifact and explore how it has affected AIDS public health policy in the United States. This thesis will argue that the Names Project AIDS Quilt is the “rhetorical centerpiece” of the AIDS movement. I will use Stewart, Smith, and Denton’s theoretical framework of the five life-cycle stages of a social movement to detail different ways the Quilt has accomplished its many goals and objectives and Burkean dramatist theories to explore the Quilt for its great source of
rhetorical power. I will outline a future for the Names Project AIDS Quilt and suggest what the future will likely hold for this rhetorical centerpiece of the AIDS movement. What I will look at in particular in this research paper is the Quilt and how it was able to make its impact on the national conversation people were having, or more accurately, not having at the time of the AIDS Memorial Quilt's creation in 1987.

Justification

This study is justified because it points out how a few committed and dedicated people, when challenged by life's circumstances, can be creative and ingenious about matters of communication no matter how grave and uncertain the circumstances they face. The AIDS Quilt is the only known memorial of commemoration designed to memorialize a civilian population by naming names of people killed, not by war, but by disease. Peter Hawkins (763) says in explanation of this phenomenon:

Epidemics are typically indiscriminate, cutting a swath through every sector of a population. The victims of AIDS, however, are by and large young; their deaths, like those of soldiers, untimely. They seem singled out for tragedy – and therefore, perhaps for memory.

And further, this Names Memorial Quilt study could serve as a model of minority initiative and activism for other populations that may face similar circumstances in the future but with the knowledge that “memorialization”, done effectively, can have a motivational impact on the population.

Historically, the 1980s were very fearful and troubling times for many reasons, but mostly because AIDS was the disease that no one wanted to talk about because of moral implications associated with it. A stigma became attached to the disease because of the early understanding that AIDS was caused by, among other things, sexual activity and
drug use. The first deaths from this mysterious disease began to appear in the early 1980's. Many of the earliest victims were gay men from urban centers in America. Because of the similarities of circumstances regarding those becoming sick, the earliest health researchers named the disease GRID or Gay Related Immune Deficiency. The researchers did not know the cause but they believed it was somehow linked to gay sexuality. Immediately, for some, this link added an immoral connotation to those who became sick and died because of complications associated with AIDS. The homophobic detractors of the gay rights movement immediately began to blame the victims who were dying because they said, "it was their lifestyle choice" that was making them sick. Thousands of people were getting sick and dying at the time and it seemed little was being done to find a cause or cure for this disease. To add insult to injury, the sick were being treated as social pariahs whose so-called immoral behavior was responsible for their own illnesses even though at the time no one really knew for certain what caused the disease.

The gay community was very torn in 1985; after many years of making progress in the fight for civil rights for gays and lesbians there was a viral enemy in the camp disabling and killing its troops. For Jones, a gay activist, it was an especially difficult time because he was seeing much of what he had worked for slip away when a good friend and political mentor Harvey Milk, an openly gay San Francisco Supervisor, was murdered in his office along with the city’s mayor on November 27, 1978. This event was tragic for Jones and as a tribute to honor his fallen heroes, he began organizing yearly candlelight vigils in their memory.
During the November 27, 1985, candlelight memorial march to honor his slain friends, Jones asked those present to honor other fallen comrades who had died of AIDS. After the march, Jones organized a demonstration at the downtown San Francisco Federal Building where he instructed the marchers to put names on placards of people who had died of AIDS and attach them to the building. Instinctively, Jones understood that as long as the AIDS casualties remain nameless, faceless human beings there was little hope of mobilizing a concerted action against the AIDS epidemic.

My intention in this paper is to analyze the Names Project AIDS Memorial Quilt and its many artifacts and memorials from a rhetorical perspective, as a movement study, to investigate how the Names Project was able to help transform the American cultural perception of AIDS. This transformation was not a simple task because of the complexities associated with the social issues related to AIDS, but I believe the Names Project played a major role in this transformation. An aspect of my research explores the covert nature with which the Names Project organizers began their mission. Were the AIDS Quilt volunteers covertly turned into AIDS activists? That is a question I will explore in this study. Regarding the claim that the Quilt was a subversive weapon of sympathy, Jones said in Poz Magazine, “I believed if you could effectively communicate what was going on...people, basically being good, would respond. And I think I was right” (Groff 66). So I will explore whether thousands of panel makers unwittingly became AIDS activists through the work of the Names Project organizers.
Review of Literature

The literature reviewed for this thesis falls into four categories: 1) studies focusing on investigations of social movements; 2) literature that contains studies focusing on the Names Project AIDS Quilt; 3) four personal interviews with Names Project AIDS Quilt founder/staff and volunteers; 4) AIDS Quilts and memorabilia associated with the AIDS movement.

Social Movement Literature

The first hurdle I shall attempt to meet in this paper is whether the Names Project Memorial Quilt meets the criteria to be considered a social movement. In his 1952 article, "The Rhetoric of Historical Movements," Leland Griffin defines three elements of movements: 1) a historical movement is something that has occurred "at some time in the past"; 2) movements are linear, that is, men become dissatisfied, then they make efforts to change their environment, then their efforts result in some degree of success or failure; and 3) movements have a historical component and a rhetorical component (Cathcart 83). The important point that Griffin was making was that historical and rhetorical components of movements are dynamic and have a beginning or inception, a development period, and a termination point when the movement has been fully consumed.

Robert Cathcart pointed out in his 1972 article, "New Approaches to the Study of Movements: Defining Movements Rhetorically," that Griffin's definition of a movement is too confining with its historical and socio-psychological limitations (83). So he
suggests the best place to look for a new rhetorical definition for movements is to Griffin's 1969 article, "A Dramatistic Theory of the Rhetoric of Movements.”

Stewart, Smith, and Denton argue that a social movement will have a life cycle consisting of genesis, social unrest, enthusiastic mobilization, maintenance, and termination. Using this theory in my thesis, I will argue that the Names Project AIDS Quilt is the rhetorical centerpiece of the AIDS movement and that according to these communication theorists, the Names Project AIDS Quilt meets these basic criteria to qualify as a social movement. Additionally, I will discuss further criteria in the movement theory chapter that Stewart, Smith and Denton contend should be met before a phenomenon can be considered a social movement.

**Names Project AIDS Quilt Literature**

Kimberly Rae Connor in her journal article, “A Common Geography of the Mind: Creating Sacred Space in the Autobiographical Writings of Paul Monette and the Names Project,” examines in great detail the spiritual aspects associated with the AIDS Quilt. She explains that the immense spiritual power of the AIDS Quilt is created when it invites Quilt viewers and panel makers alike to cross boundaries and share experience “through spiritual engagement and empathetic identification.” Further defining the source for the spiritual power that many Quilt visitors describe she argues that “The Quilt is an ongoing attempt to define the boundaries of the disease and to construct some meaning about its impact on human lives”(48).

Mary Beth Krouse, a professor of Sociology and Anthropology at Ohio State University, in her article, “The AIDS Memorial Quilt as Cultural Resistance for Gay
Communities,” argues that “The Quilt’s implications for certain gay communities... include its tendency to draw gay men out of physical and social isolation into collective experience...” What I will show in this thesis is how this “collective experience” has had a tremendous impact on the Quilt’s ability to mobilize and motivate groups of Quilt volunteers to become front line AIDS activists (65). A second article by Professor Krouse, “Gift Giving, Identity, and Transformation: The AIDS Memorial Quilt,” focuses on the Quilt’s construction as a “gift” as an “inalienable possession” that maintains “historical identity and immortality for its originators, many of whom are gay and bisexual men.” Further, she discusses the notion of the Quilt as an “erotic gift” which has the impact “to draw people together, create feeling bonds among them and affect their transformation” (Krouse, Gift Giving, Identity, and Transformation 241).

Peter S. Hawkins, a professor of religion and literature at the Yale Divinity School, in his journal article, “Naming Names: The Art of Memory and the Names Quilt,” argues, “In the patchwork quilt, then Jones discovered the domestic equivalent for the sign of national unity. It offered a metaphor of e pluribus unum, but it was also a brilliant strategy for bringing AIDS not only to public attention but into the mainstream of American myth – for turning what was perceived to be a ‘gay disease’ into a shared national tragedy” (757).

Judy Elsley, a professor of English from the University of Arizona, in her journal article, “The Rhetoric of the Names Quilt: Reading the Text(ile),” argues that the Names Quilt has been a popular and effective response to the AIDS epidemic because it “dissipates a monolithic and prejudicial central power into a myriad of individual voices, each claiming power for itself without setting up competition with others” (192).
major argument she makes in her article is that the quilt's many voices resist the silencing that constitutes the culture's most effective way to marginalize AIDS and PWAs. She argues her theory utilizing the AIDS and "military metaphor" theory of Susan Sontag and M.M. Bakhlin's theory that the Names Project AIDS Quilt operates as a "open ended, protean, populist, cultural critique" that resembles a novel, which draws its power from grassroots countercultural activity (Nelson 191).

AIDS History Resources

Randy Shilts, a San Francisco Chronicle writer, in his book The Band Played On: Politics, People, and the AIDS Epidemic, gives an encyclopedic account of the first decade of the AIDS epidemic. In this account, he tracks the early story of AIDS and documents how the federal government consistently put budget considerations ahead of the nation's welfare, how the health authorities placed political expediency ahead of public health concerns. This book presents a stinging indictment of the many American health and government institutions, showing clearly how they failed the American people.

John-Manuel Andriote, a Washington-based journalist, in his book, Victory Deferred: How AIDS Changed Life In America, gives an up to date account of the impact of the disease and he shows how it changed lives, communities, and organizations. In his book he quite simply states, "the Quilt despite criticism that it hasn't been political enough, it has by itself arguably done more to increase awareness of the human toll of the epidemic – and of the humanity of those it memorializes – than all the nation's gay political organizations combined" (367).
Other sources consulted in this study were Jones' autobiography, *Stitching a Revolution, the Making of an Activist* (2000); *A Promise to Remember, The Names Project Book of Letters and Remembrances of Love from the Contributors to the Quilt* edited by Joe Brown (1992). Another source of material for my study is a book published by the Names Project, *The Quilt – Stories from the Names Project*, written by Cindy Rushkin (1988). Another resource that will be used in my research is a chapter in the book, *Living with AIDS – A Photographic Journal* by Sal Lopes (1994). In this book, along side many touching photos of quilts and stories about the persons who have died of AIDS, are journal entries written by AIDS buddies dedicated to the persons memorialized in the panels. They tell touching stories of loss along with flourishes of hope and empowerment to suggest that accompanying the grieving was another accompanying process, making people stronger and willing to fight to end the suffering they have witnessed. This “fight” would take many forms and I will explore how the rhetoric associated with the AIDS Quilt helped people on a personal level, but also how these personal feelings were transformed into action that changed our culture by forcing the American people to reevaluate their judgments and increase their willingness to help stop the suffering associated with the disease called AIDS.

**Methodology**

This research project will use multiple methodologies. The two methods I will use to tell the story of AIDS and the Quilt will be ethnographic and autoethnographic in design. Using these two methods, I will rely on theories of Burke to explain why I think the AIDS Quilt has been so successful in its mission to reframe the losses caused by the
AIDS epidemic and how this artifact was essential to galvanize and strengthen the American community's response to AIDS.

Social research scientists Paul Atkinson and Martyn Hammersley say of Ethnography:

That it refers to a philosophical paradigm to which one makes a total commitment, for others it designates a method that one uses as and when appropriate. And, of course, there are positions between these extremes. In practical terms, ethnography usually refers to forms of social research having a substantial number of the following features:

- 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 analytical categories.
- Investigation of a small number of cases, perhaps just one case, in detail.
- Analysis of data that involves explicit interpretation of the meaning and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations, with quantification and statistical analysis playing a subordinate role at most.

With these points in mind, reflection suggests “exploring the nature of particular social phenomena” could very well be an exploration of the need for a “visual instrument” or AIDS Quilt to guide American society toward a more proper and human understanding of the mounting losses occurring in the AIDS pandemic. Regarding the “unstructured data”, commonly associated with ethnographic study, I assert that my four
interview subjects provided me with ample valuable “data” that will be used to support my primary thesis. These four subjects were each asked approximately the same sixteen questions. The interviews generally lasted between one to three hours and they were tape recorded and transcribed. For the purpose of consistency, it was my goal to ask each subject the same questions with the intention that the subjects would then focus on different questions within the overall set so that when research is complete, I would be able to present a case that reflects the subject’s accurate and thoughtful viewpoints about their personal relationship to the AIDS Quilt with the intention that the information gained will support my thesis.

A second methodology I will use in this paper will be autoethnographic in design. The purpose in including this methodology is to allow me to contribute “my personal story” as it relates to the AIDS movement and to the story of the Quilt as a “rhetorical artifact.” Communications scholars Carolyn Ellis and Arthur Bochner define the genre this way, “Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural…focusing outward on social and cultural aspects of their personal experience”(Ellis and Bochner 739). Further Ellis and Bochner identify a type of autoethnographic writing as personal narrative and explain this is exhibited when “social scientists take on the dual identities of academic and personal selves to tell autobiographical stories about some aspect of their experience in daily life”(Ellis and Bochner 740). Following this definition, my reasons for choosing this second methodology seem obvious to me. I have been affiliating with the Names Project AIDS Quilt since 1989 when I joined a friend to induct a quilt panel he made for a mutual friend who had recently died from AIDS. But the
interest became more personal when, on my birthday in August 1991, I was delivered the news that I had seroconverted to HIV+. Three years later, in 1994, I was officially diagnosed as living with AIDS after a prolonged bout of illnesses. Since my introduction to the Names Project AIDS Quilt, I have visited it many times both locally and at the nation’s capital twice. The spiritual power it generates is immense and awe inspiring to witness and this study will focus on explaining that power.

In many ways Jones was on a fool’s errand – *jousting at windmills* – in his attempt to get the powers that be in the U.S. government to pay attention and address the losses that were mounting because of deaths from AIDS. Ronald Reagan would not even mention the word AIDS, let alone address the many problems associated with the epidemic that was killing thousands of Americans. The story of the AIDS losses was not being told to the American people by its leaders and the job needed to be done, none the less, and it fell on other shoulders. Kenneth Burke’s Dramatist theories of hierarchy, acceptance and rejection, guilt, purification, redemption and identification seem perfect for application in the study of the Names Project AIDS Memorial Quilt as a rhetorical “visual instrument” designed and conceptualized with the intention of helping the American people reframe and better understand the human losses associated with the AIDS epidemic.

Burke’s theory of rhetoric embodied in his dramatistic approach is comprised of several major concepts. Rhetorical scholars Rybacki and Rybacki explain, “the first major concept in Burke’s theory of rhetoric is that when people use language – that is, verbal symbols – they are acting in response to some situation” (Rybacki and Rybacki 68). Explaining the second major concept of Burke’s dramatistic approach, they further explain, “that society is created and maintained through symbols, which are used to
control behavior” (Rybacki and Rybacki 70). Following that, they say, “human action involves using symbols, and social drama is the form this action takes” (Rybacki and Rybacki 70). Rybacki and Rybacki conclude by noting “a drama implies the presence of conflict in the social order. Society represents a dramatistic process of hierarchy, acceptance and rejection, guilt, purification, and redemption” (Rybacki and Rybacki 70). These categories of psychological feelings will be used in my research paper to study the Names Project AIDS Memorial Quilt and its supporting movement of AIDS activists.

The last Burkean concept I will use is that of identification. Rybacki and Rybacki explain, “Burke’s theory of rhetoric is based on how people communicate in pluralistic societies: Rhetoric must be viewed as identification rather than persuasion because its function is to proclaim unity” (Rybacki and Rybacki 74). Explaining his theory, Burke said, “A is not identical with his colleague B. But insofar as their interests are joined, A is identified with B. Or he may identify himself with B even when their interests are not joined, if he assumes that they are, or is persuaded to believe so” (Burke 20). Rybacki and Rybacki conclude, “In Burke’s dramatistic approach, rhetoric is a symbolic means of creating cooperation” (Rybacki and Rybacki 74). Using Burke’s theory of identification, I will research the community of activists who were assembled as quilt panel makers and volunteers, whenever the Names Project AIDS Quilt was exhibited to explore the connection between Identification and the needs of the community.

The final concept I will explore in this paper concerns how the AIDS Quilt has been used in the past and its aspects for a future. Originally it was conceived as an organizational tool. At its first display, it immediately became a mourning tool. Other more recent uses find that the AIDS Quilt is an educational tool, and now it has become
an AIDS prevention tool. Why? Could the Names Project AIDS Memorial Quilt become
the primary AIDS prevention tool in our culture’s arsenal of preventative measures? Or
perhaps the World’s answer to the fight against AIDS?
CHAPTER 2

THE AIDS QUILT GOES TO WASHINGTON

Movement Theory

Is the AIDS Quilt a rhetorical centerpiece of an AIDS movement in America? The inaugural display of the Names Project AIDS Quilt occurred in Washington, D.C., on October 11, 1987. It covered a space larger than a football field and included 1,920 panels. A half a million people visited the Quilt. Today, there are 35 Names Project chapters in the United States and 46 independent Quilt affiliates around the world and since 1987 over 14 million people have visited the Quilt at thousands of displays worldwide. Through such displays, the Names Project Foundation has raised over $3 million for AIDS service organizations throughout North America. So with this brief history in mind, I suggest the AIDS Quilt meets a qualification to be considered the rhetorical centerpiece of the "AIDS movement" because in its frequent displays the AIDS Quilt has heightened awareness about the people lost to AIDS and it has been instrumental in organizing people to fight back against AIDS in a variety of ways.

In his 1952 article, "The Rhetoric of Historical Movements," Leland Griffin defines three elements of movements: 1) a historical movement is something that has occurred "at some time in the past"; 2) movements are linear, that is, men become dissatisfied, then they make efforts to change their environment, then their efforts result in some
rhetorical component (Cathcart 83). I suggest the AIDS quilt qualifies on all three of these elements as defined by Griffin. Since its inception in 1987, the AIDS Quilt has developed a historical record of activism during its many displays. The Names Quilt mission statement speaks to the desire to change the way America responds to the AIDS epidemic and stories contained in the Quilt have a self evident rhetorical component that informs Quilt viewers about the lives of those lost to the AIDS disease. The most important point Griffin makes is that the rhetorical component of a movement is dynamic, has a beginning or inception, a development period, and a termination point when the movement has been fully consumed.

Robert Cathcart in his 1972 article, “New Approaches to the Study of Movements: Defining Movements Rhetorically,” attempts to move beyond Griffin’s definition of a movement because it’s too confining with its historical and socio-psychological limitations (Cathcart 83). Cathcart concludes that the historical approach to movement study cannot accurately predict when movement becomes a movement and he seeks to expand the rhetorical definition by arguing the best place to look for a new rhetorical definition for movements is in Griffin’s 1969 article, “A Dramatistic Theory of the Rhetoric of Movements.” In this article, Griffin uses a Burkean analysis and theorizes that “All movements are essentially political, concerned with governance or dominion, the wielding and obeying of authority; that politics above all is drama; and that drama requires a conflict...all movements are essentially moral – striving for salvation, perfection, the good” (Griffin 456). With Griffin’s Burkean analysis in mind, I assert that the AIDS Quilt qualifies as centerpiece status of an AIDS movement because it has focused “dramatic” attention on people with AIDS, arguing for recognition of the
humanity of the sufferers and because it is a moral issue. Cleve Jones said in my personal interview that the AIDS Quilt was successful at its mission because it "claimed the humanity of those we have lost saying all these lives are valuable" (Jones, Cleve Personal Interview. March 17, 2001).

Stewart, Smith, and Denton (3-17), argue that a social movement has a life cycle consisting of genesis, social unrest, enthusiastic mobilization, maintenance, and termination. Using this theory as a basis, I argue that the Names Project AIDS Quilt should qualify as a rhetorical centerpiece of the AIDS movement because the Names Project AIDS Quilt meets these basic criteria and therefore qualifies as a social movement. Additionally, Stewart, Smith and Denton (3-17), suggest additional criteria that should be met for a phenomenon to be considered a social movement. The Stewart, Smith and Denton list of criterion are: a social movement has at least minimal organization, a social movement is an uninstitutionalized collectivity, a social movement is large in scope, a social movement proposed or opposed a program for change in societal norms, values or both, a social movements rhetoric is moral in tone, a social movement is countered by institutions, and persuasion is pervasive in social movements (3-17).

Regarding the "uninstitutionalized collectivity," it should be noted that the Quilt has no official status, no public funding, no fixed location in Washington, indeed no single place where it can be seen as a whole any longer. Its increasing size, and the fact that it can barely be contained or even experienced all at once, serve to dramatize a present reality over which we seem to have no control. In fact, during the first four Washington, D.C. displays of the Names Project AIDS Quilt, which was placed across from the street...
from the White House, the home’s occupants both Presidents Reagan and Bush left home and looked the other way. Peter Hawkins (776) notes that “Although boycotted by the powers that be, the Quilt has nonetheless made an assault on official oblivion. Occupying the Mall for a weekend at a time, it has claimed the traditional site of not only governmental authority but of civil protest against it.” Agreeing with this appraisal, I further suggest that the Names Project AIDS Quilt meets the second criteria of having no “institutionalized collectivity.”

The size and the scope of the Names Project AIDS Quilt could be measured in a variety of ways to determine its viability as a “social movement”. Beginning in 1987, the Quilt has been brought to and assembled on the National Mall in Washington, D.C. five times plus there have been two national tours of North America that stopped at forty cities. According to Jones, as of the year 2000, there have been 14,542,000 visitors to the Quilt; there are over 44,400 panels in the AIDS Quilt; there are 80,466 names on the Quilt. There are 48.75 miles of fabric in the quilt – the distance greater than that between Providence, Rhode Island and Boston, Massachusetts, and it currently weighs 53 tons. But the critical statistic regarding the “social movement” criteria are the 1,229,540 volunteer hours amassed by the many volunteers in the 35 Names Project chapters in the United States and 46 independent Quilt affiliates around the world and since 1987. These volunteers, through their dedicated service to the Names Project AIDS Quilt, have been AIDS activists at the forefront on the fight against the societal indifference to AIDS and its sufferers and in the fight against the continuing spread of the AIDS disease through education and prevention. As to whether the Names Quilt proposed or opposed a program for change in societal norms, values or both as a qualification to be considered a
social movement, I suggest the following litany of organizational goals qualifies the Names Quilt overwhelmingly. The goals are: To provide a creative means for remembrance and healing, to illustrate the enormity of the AIDS epidemic, to increase public awareness of AIDS, to assist with HIV prevention education, to raise funds for community-based AIDS service organizations.

As to the criteria that the “social movement’s” moral tone must be considered, I submit the mission statement of the Names Project AIDS Quilt – “To use The AIDS Memorial Quilt to bring an end to AIDS” is highly sufficient and add as a memorial, a tool for education and a work of art, the AIDS Quilt is a unique creation, an uncommon and uplifting response to the tragic loss of human life and it stands at the forefront of the persuasive strategies that have been mounted against AIDS, the last epidemic of the Twentieth Century.

Further supporting my assertion that the Names Project AIDS Memorial Quilt can be viewed as a rhetorical component and driving force behind a social movement, I look to the work of rhetorical scholar Robert S. Cathcart a second time. Again using a Burkean dramatistic argument in his 1972 article “New Approaches to the Study of Movements: Defining Movements Rhetorically,” Cathcart said, “It is this reciprocity or dialectical enjoinment in the moral arena which defines movements and distinguishes them from other dramatistic forms” (87). Further explaining he said,

The essential attribute here is the creation of a dialectical tension growing out of moral conflict…rather, it is the formulation of a rhetoric proclaiming that the new order, the more perfect order, the desired order, cannot come about through the established agencies of change. and this, in turn produces a counter-rhetoric that exposes the agitators as anarchists or devils of destruction.

(87)
My understanding of Cathcart’s meaning is that a movement exists when the established order resists change and the ensuing dynamic creates moral drama. With that in mind, I will present further research in this paper to provide evidence that the American government and its “established order” as well as society in general resisted change as it grappled with how to fight this new threat to the health of the American public.

Symbolism is at the heart of the Names Project AIDS Memorial Quilt. For this reason I will be relying on many of Kenneth’s Burke’s theoretical approaches when analyzing the AIDS Quilt itself and the Names Project as a social movement.

The definition of “social movement” is not concrete as it elicits different definitions from different theorists. William Bruce Cameron, offering a collective action definition, says: “a social movement occurs when a fairly large number of people band together in order to alter or supplant some portion of the existing culture or social order” (Stewart, Smith and Denton 2). Herbert Simons defines social movements as “struggles on behalf of a cause by groups whose core organization, modes of action, and/or guiding ideas are not fully legitimized by the larger society” (Stewart, Smith and Denton 2). Citing these definitions, I asked Jones about the social/psychological/political climate in San Francisco in the mid 1980’s. My intention with these questions was to verify there was a group whose intention was to “alter or supplant...existing culture.” To my specific question about the “primary driving emotions in the San Francisco gay community”, Jones responded:

Certainly for me and my friends the predominate emotions were fear, hate, and despair. Fear of getting sick and dying and hatred for the administration and a heterosexual world that was ignoring what was happening and despair that there just didn’t seem to be any hope (Jones, Cleve. Personal Interview. March 17, 2001).
This bleak analysis was not unique to San Francisco and may have been amplified because that city was so devastated by the disease, but I can attest that those same feelings were being felt by others in gay communities coast to coast. This being the reality it is not difficult to understand how the Names Project AIDS Quilt was able to create and sustain a grassroots network of volunteers who helped by making and organizing displays of AIDS Quilts to honor and memorialize loved ones lost to AIDS.

Seeking to fit the AIDS Quilt into Stewart, Smith, and Denton's theoretical framework of the five lifecycle stages of a social movement, I asked Jones to verify the historical timing of each stage; 1) Genesis 2) Social Unrest 3) Enthusiastic Mobilization 4) Maintenance 5) Termination. Jones confirmed the genesis happened on November 27, 1985 when he saw his vision on the Federal Building wall. Further, he remarked that the social unrest period took place between 1985-1987. His belief regarding the enthusiastic mobilization period was that it took place between 1987-1996. Proudly, he noted that in the 1996 over one and a half million (1,500,000) people went to Washington, D.C. to view the Quilt during what is believed to be the last viewing as a whole display. What is all the more remarkable is that this gigantic crowd came out for just the Quilt showing as there were no Gay Pride activities going on at that time. During this display, the Names Project AIDS Quilt filled the entire park mall area between the Washington Monument and the U.S. Capital.

As I reviewed the five stages of a life cycle of a social movement with Jones, he added a possible sixth, between 4) maintenance and 5) termination, which he called mutation. The point Jones was expressing is his belief that the Names Project AIDS Quilt is currently transforming itself, not willing to terminate because the AIDS epidemic is not
over and the founders and organizers of the AIDS Quilt will not relinquish their mission
to “claim the humanity” of those lost to AIDS until the epidemic ends.

There are primarily three types of research material I will use in this paper. The first
will be original research from personal interviews with original founders, organizers,
staff and volunteers associated with the Names Project AIDS Quilt. The second will be
current academic research regarding the Names Project AIDS Quilt. The third type of
research material I will analyze will be Quilt artifacts themselves; Names Project
brochures, speeches of its organizers, public presentations materials, rallies, and
volunteer coordination and quilt making seminars for clues as to how the AIDS Quilt
performed its role transforming the public perception of the human loss caused by the
public health catastrophe of the AIDS epidemic.

Explaining his theory for the overwhelming success of the transformative role of the
AIDS Quilt, Peter Hawkins (757) said: “In the patchwork quilt, then Jones discovered the
domestic equivalent for the sign of national unity. It offered a metaphor of *e pluribus
unum*, but it was also a brilliant strategy for bringing AIDS not only to public attention
but into the mainstream of American myth – for turning what was perceived to be a ‘gay
disease’ into a shared national tragedy.”

Rhetorical Theory

Elizabeth Taylor eloquently spoke of the power of the Names Project AIDS Memorial
Quilt when she was addressing the 150,000 Candlelight marchers during the closing
ceremony at the 1996 Quilt display on the National Mall in Washington, D.C. She said:
The Quilt has taught us much about how elegantly life can be lived and how quickly it can be lost. This Quilt invites us to step into the private space of people's lives, where we can share in timeless, personal moments. In order to go forward we must go back, we must acknowledge the grief and the love, confront the collective pain, to achieve a hard-won sense of peace. Then and only then can we focus our energy and anger at the real enemy, the virus itself. The Quilt shows us that although we are all different, we are all the same. (Jones & Dawson, 2000, p. 243)

James R. Andrews, in his article "History and Theory in the Study of the Rhetoric of Social Movements," says: "A collective must first be conscious of itself. Any movement must deal somehow with social perceptions of reality by using rhetoric to alter, shape, and extend the ways in which the world is seen by those living in it." (279)

So it was the challenge of the founders of the Names Project AIDS Quilt that they set about to "alter, shape, and extend" the societal definition of who it was that was getting AIDS in America, to be self evident as Elizabeth Taylor noted, primarily people who "are all the same." The challenge was great but the AIDS Quilt's founders fought mightily for many years on behalf of the countless people with AIDS in America.

When the AIDS Quilt was first displayed on the National Mall in Washington, D.C. in October 1987, it contained nearly two thousand handmade panels honoring those who had died of AIDS. A year later, in 1988, the Quilt had grown to almost nine thousand handmade panels when it was spread out on the ellipse, south of the White House. In preparation for this display, the Names Project volunteers took the Quilt on a twenty-one city national tour from March to July 1988 which raised $500,000 for hundreds of local AIDS service organizations.

In October 1990, the Names Project displayed five thousand panels each simultaneously in five cities; Houston, Atlanta, Chicago, Los Angeles, and Washington,
D.C., where a total of 100,000 people visited the Quilt at these showings. Cleve Jones wrote in The Names Project Newsletter in September 1990, “It has been three years since the quilt was first displayed on the mall in Washington, D.C. Since then the numbers of dead have grown from 27,000 to nearly 100,000 and the quilt has grown from 1,920 panels to over 12,000” (Nelson 187). The overwhelming growth of these statistics lead to the question of why has the AIDS Quilt been so effective at mobilizing a response to the AIDS epidemic. In this section of this chapter, I will attempt to address that question by explaining how making AIDS Quilt panels provided rhetorical means, which helped significantly to change the characterization of who America believed was really being affected by the AIDS epidemic.

Making AIDS Quilt panels provides survivors the ability to make a difference. AIDS is a devastating disease that leaves caretakers feeling helpless in terms of healing those afflicted with AIDS. In contrast, making a quilt panel is something over which panel-makers have complete control. “Making a panel provides the griever with a way to begin to deal with their loss” writes quilt researcher, Judy Elsley (Nelson 188). To explain, Elsley notes that AIDS Quilt historian Cindy Ruskin says, “These are not stories of an illness... rather they are stories of courage, fear and anger, and mostly they are stories of love” (Nelson 188).

At all AIDS Quilt displays, the quilt volunteers recognize the need to express loss and consequently provide an appropriate and supportive context to express loss and grief. Boxes of tissues are readily available from the white clad volunteers in attendance. Attendees are expected to weep at AIDS quilt ceremonies. “The quilt is not offered as entertainment. It’s supposed to be excruciating,” says Cleve Jones (Bellm 35).
Explaining the constructive role of funereal like rituals, Elsley says, “Grief is, to some extent, formalized and ritualized so that it becomes if not manageable at least acceptable” (Nelson 188). The Quilt rituals, with all their funereal rites, including naming names, are a significant aspect of the rhetorical assault against the preconceived notions that only “bad gay people” get AIDS.

The AIDS quilt is much like the Vietnam War Memorial to which it is often compared. Each names names of those lost. They each seek to claim the humanity of the person named so that the loss is not treated solely as a statistic. The Names Project AIDS Quilt goes further though to restore indirectly and by extension dignity to those who have died of AIDS. Each panel tells a story of the individual lost and of the panel maker. Each panel, when it is given up to the Names Project is accompanied by a letter from the maker, explaining the thoughts and feelings of the survivors. “What they do,” says Cleve Jones, speaking of their survivors, “is they come to the quilt, and they cry, and then they empty their pockets, and then they sign up and get to work. We’ve seen that over and over” (Bellm 35).

Elsley, speaking of the extraordinary response the AIDS Quilt has produced, says, “This is a remarkable response when we consider the aversion the disease so often invokes, encompassing as it does a particularly toxic set of fears: fear of homosexuality, of a plague striking young people, and of death” (Nelson 188). Explaining further the complexity of our cultural response to AIDS, Phil Nash observes, “AIDS threatens the ideals on which all our cultural values are balanced: the quest for love and the fear of death. The stunning and paradoxical reality of AIDS is that death – for many the greatest fear – has found its way into our most passionate and tender moments” (Nash 9). Because
AIDS embodies our worst fears, it is much easier to marginalize, through disgust and rejections, than to face directly. But paradoxically what we cut out is also what defines us. Stallybrass and White (4) explain this paradox in the Politics and Poetics of Transgression when they say:

The “top” attempts to reject and eliminate the “bottom” for reasons of prestige and status. only to discover not only that it is in some way frequently dependent upon that low-Other. but also that the top includes that low symbolically...The result is...a psychological dependence upon precisely those Others which are being rigorously opposed and excluded at the social level. It is for this reason that what is socially peripheral is so frequently symbolically central.

So the AIDS Quilt is symbolically perfect for the issues it raises, those of disgust and desire. Traditionally, a quilt represents the comfort and security of home and often its place is on the bed. Elsley explains the dichotomy of this view when she notes:

There is a subtle interplay between what we most fear – death from AIDS - and a quilt that we associate both with domestic security and comfort, and with the bed, a place of procreations. Life and death meet in the AIDS quilt. That comingling helps both to dissipate the fear and to remind us that no one is immune. By employing a quilt, the Names Project brings AIDS literally and metaphorically home. (Nelson 1989)

The struggle against "fear and prejudice" is embodied throughout the text of the Quilt. But the fear is not fear of the virus itself that is most noted but generally it is fear of the equally destructive enemies of ignorance, hysteria, and bigotry that are addressed. Though the Quilt offers no solution to the physical virus, it does attempt to cure the national ills of "fear and prejudice." Because after seeing these panels, we can no longer dismiss the victims as promiscuous perverts who got what they deserved. Stories are told within the Quilt panels that speak of the common values of partnership, celebration, love, family, and loss. Elsley explains the importance of this when she says:
The quilt, then, works as a symbol, but it also works as rhetoric. This quilt quite literally invites a reading - the panels are the leaves of an enormous textile text. Speaking its complex visual, verbal, and nonverbal language, the NAMES Project quilt sets about claiming power for people with AIDS by creating a story of their own making, for the victims, panel makers, and even those who come to see it. (Elsley 189)

Carroll Smith-Rosenberg explains in Disorderly Conduct that "Language is not limited to words." Further she continues: "If by 'language' we mean symbolic communication, then a host of nonverbal forms can be adopted. Dress and food codes, religious rituals, theories of disease etiology, the varied forms of sexuality, all function in societies around the world in highly expressive ways" (Nelson 189). The Names Project AIDS Quilt acts in just such a highly expressive way seeking to combat the rhetorical predispositions of the dominant culture which has attempted to marginalize and separate the AIDS affected community.

Quilt makers are well aware that he who possesses the rhetoric possesses the power. One way to begin claiming the rhetoric is to provide a way to speak about AIDS that avoids the harmful language of difference and discrimination. Susan Sontag argues in AIDS and Its Metaphors, "much in the way of individual experience and social policy depends on the struggle for rhetorical ownership of the illness: how it possessed, assimilated in the argument and in the cliché." She goes on to point out that AIDS has been "possessed" by political and military metaphors that have set up an opposition between "we" who are healthy and "they" who are sick dichotomy (Sontag 48). According to Sontag, such an opposition is dangerous because the "non-us" are also constituted as foreign, wrong, guilty (Sontag 48). Further explaining, she says that the us and them, winners and losers, healthy and sick, rhetorical dualities represent the binary
oppositions that lead to ultimately to the underlying pairing of "superior" vs. "inferior."

Examples of the pairing of "superior" vs. "inferior" can be found even in simple apparently innocent language that attempts to define who is most likely to become affected by AIDS. The use of the term "risk group" for example is a "neutral-sounding, bureaucratic category which also revives the archaic idea of a tainted community that illness has judged" (Sontag 46). The Names Project, which is well aware of the power of rhetoric, suggests in its press releases that journalists employ the phrase "Person with AIDS" rather than "victim" because "the use of 'victim' creates the false impression that people with AIDS are distinct from everybody else" (Nelson 190). Making the point regarding this suggestion, Elsley argues, "The Names Quilt provides an opportunity for people with AIDS (PWAs) to repossess the rhetoric and thus reinscribe their stories so that they can claim dignity and status for themselves rather than be marginalized into mere victims" (Nelson 190).

The most common non-verbal rhetorical artifacts associated with the Names Project are the Quilt panels themselves. There are no instructions to the quilt panel makers other than the size of the panel itself must be three by six foot, the size of a burial plot. The range of panel designs vary from simple to ornate. Many use items to represent the loved one who has been lost. Just about anything that can be sewn into fabric can be used. Items of clothing that the panel makers remember the loved one wearing are favorite items for inclusion on the panels.

An example is my friend Paul's quilt, which has his U.S. Navy jersey sewn onto his quilt along with a large 8 x 11 picture of him taken when he was the picture of health. Merit badges, teddy bears, wedding rings, shirts and ties, leather and lame, just about
anything goes when it comes to the quilt materials and designs, even cremation ashes have been sewn into memorial quilts. A quilt I personally made for eight friends, which became a part of the national quilt on October 11, 1992, simply listed their names in gold on a black background. Sewn onto the background fabric was a shiny gold box with adornment ribbon and a short tribute that said, “Memories of you are golden treasures cherished in my heart forever.” I signed it, “Love Daniel,” and gave it up to the quilt volunteers with tears in my eyes.

Another ceremonial ritual used by the Names Project, which is always included during an AIDS Quilt public display is the Names Project’s insistence upon naming names. At every Names Project event this ritual takes place. Peter S. Hawkins (752) explains the importance of this ritual when he says:

Human beings are alone in imagining their own deaths; they are also unique in their need to remember the dead and to keep on imagining them. Central to this act of memory is the name of the deceased, that familiar formula of identity by which a person seems to live on after life itself is over. To forget a name is in effect to allow death to have the last word. For this reason the common impulse of grief is the reiteration of personal names and the titles of relationship, it is to cry out like King David, ‘My son Absalom; O Absalom, my son, my son’ (2 Sam. 19:4-5), as if by the force of repetition it might be possible to conjure up the one who is lost.

Dramatist Theory

Burkean Analysis

The study of social movements is an endeavor that requires familiarity with theories of sociology, psychology, history, and communication. Social movements are complex and dynamic entities that have been responsible for some of the greatest changes in
America’s history. There are multiple communication theories that are believed to have an ability to explain social movements. Kenneth Burke, a philosopher, writer, and postmodern thinker, developed many rhetorical theories to explain how communication takes place and how it has affected our society. I argue that Burke’s theories are certainly applicable to the study of the AIDS Quilt as the rhetorical centerpiece of the AIDS social movement. The dramatistic approach that Burke developed embodies Shakespeare’s claim that “all the world’s a stage.” Whether a rhetorical actor is making a speech, writing a book, making a movie, or educating the public by organizing a protest demonstration using an AIDS Quilt as the rhetorical centerpiece of the event, the rhetor is taking part in a social drama while living in and responding to society.

The first major concept in Burke’s theory of rhetoric is that humans are symbol using creatures who use symbolism to communicate with each other. Burke says that rhetoric is symbolic action. His belief is that humans use and misuse symbols to say what they are not, which is a uniquely human capability (Rybacki and Rybacki 68). Further explaining this, Burke says that humans invented the negative use in communication and that this is what enables humans to moralize about what is permitted and prohibited behavior. Arguing that communication is at the very core of what it means to be human Rybacki and Rybacki say:

In Kenneth Burke’s dramatistic philosophy, the ability to symbolize verbally is the defining characteristic of humanity. As symbol users, humans are also actors. Verbal symbols enable us to perform many kinds of acts: to define, to accept, to reject, and to pursue the ultimate good. Communication explains what being human is, what problems humans face, how humans should act, and how the ideas and concepts of other humans are to be used. (Rybacki and Rybacki 68)
A distinction that Burke creates is to note that humans are distinct in nature in that they create action purposefully to make changes that they believe are necessary for whatever reasons they believe are important. A further distinction that Burke notes is that action is different from naturally occurring motion like birth, death and the physical drive to maintain life and the naturally occurring change of seasons. Rybacki and Rybacki explain: “Action is the counterforce to motion in the substance of humanity: Nature moves, people act. People are still part of nature, but they use action to overcome nature and to respond to situations in the natural realm” (Rybacki and Rybacki 68). Further explaining this, Rybacki and Rybacki say, “Action and the sense of morality that comes from acting differentiate humans from the rest of the creatures in the natural world. Instead of just letting things happen, people give elaborate reasons for why they eat, defend territory, take mates and so on” (Rybacki and Rybacki 69).

The motion-action dichotomy is important to the rhetorical critic because it defines people as distinct symbol using creatures who use language as the primary mechanism for creating action. This is important because this distinction sets humans apart as they use language as the primary mechanism to create purposeful change to the human condition. Whether it’s speeches, songs, editorials, or AIDS Quilt demonstrations, it is possible to use rhetorical activity to focus a societal consensus on how people should all cooperate as fellow human beings. As a philosophy of human communication, dramatism broadens the concept of rhetorical activity to include all literature and speech as a response to human situations.

A major part of Burke’s dramatistic theory of communication articulated in his Language as Symbolic Action is that society is created and maintained through symbol
use and the overriding purpose is to control behavior (Burke 1966). Burke’s dramatistic theory is comprised of several components: Hierarchy; Acceptance and Rejection; Guilt, Purification and Redemption; and Identification. Burke’s dramatistic theory is rich with psychological motives and its complexity is very interesting and offers a flexible family of methods for rhetorical criticism.

Regarding the second concept, according to Burke, society has an overriding need for organization and hierarchy. Rybacki and Rybacki explain Burke’s hierarchy theory:

Hierarchies in the social order are structures that divide people into categories that are based on the power – social, economic, or political – that they possess. Power is never evenly distributed in a society. Some people always have authority over others and power determines this authority.

When the power structure changes, shifts in authority usually follow. (Rybacki and Rybacki 71)

Hierarchies are not inflexible and change is inherent in both action and motion because hierarchies always try to provide for orderly change. A clear example of a hierarchy managing an orderly change is the democratic process of holding elections to manage the orderly change of the leadership of our American government. But within governments, managing change in their hierarchies are not always clean and organized because there are not always good mechanisms for orderly change. This problem is compounded when there are people and organizations outside of the power structure working against the system because they feel the dominating system is making an error for some reason.

The AIDS movement is a perfect example of a social movement that began its organization because of the government’s unwillingness to act against a perceived social problem, the disease called AIDS. The government’s failure was on many levels but most specifically the AIDS movement originally mobilized because the Federal Drug Agency (FDA) failed to expeditiously support new drug investigations to combat the HIV
virus that causes AIDS. As more and more people got sicker and sicker, the need for social services became more apparent and there was additional pressure applied throughout the government to address the multiple AIDS issues that were being created because thousands of Americans were getting sick from this newly discovered disease.

The two concepts of acceptance and rejection are used by Burke to explain how his dramatistic theory of communication works. In a drama, there will be conflict in support of or against the controlling hierarchy. Because symbol use can be positive or negative, friendly or unfriendly, people have the ability to accept or reject the social order and their position in its hierarchy. Acceptance is the positive or friendly reaction to the hierarchy; rejection is a negative or unfriendly reaction. Rejection results in alienation or disorder.

If you look at the beginning of the AIDS movement, it is readily apparent that the Reagan government was rejecting the concept that the government had a role to play in fighting against the spread of the AIDS disease. This rejection by the government caused the AIDS activists to reject their government because it was not doing enough to find a cure for AIDS or provide the social services for people sick with AIDS. But the concepts of acceptance and rejection as a part of a social drama is apparent on a personal level also and not just as it relates to the AIDS movement. During the early part of the AIDS epidemic, there was considerable rejection of people with AIDS as their families and friends rejected them as they became sick with this new disease. This rejection was hurtful in many ways to the people with AIDS and it was the primary thing that Cleve Jones was trying to counter with the AIDS Quilt on both societal and familial grounds. How the AIDS Quilt was able to counter the rejection that was disproportionally affecting the gay community, which was being disproportionally affected by the AIDS
epidemic during the early years of the epidemic, can be effectively explained by using Burke's theories of Guilt, Purification and Redemption.

Kenneth Burke tended to see all hierarchies and social orders as continually engaged in dramas. Burke believed: “Action occurs because people object to the functions and relationships imposed by hierarchical structure” (Burke 1965). These hierarchies are not just political but they are noted in families, careers, churches, schools, and assorted interest groups. According to Burke, when a person is conflicted because of loyalty to two different hierarchies, this causes feelings of guilt. The repercussions of guilt can be profound. According to Duncan “As a psychological state, guilt is uncomfortable because it leads to fear, stress, and the potential loss of order” (Duncan 1968).

Families became torn by guilt because of the AIDS disease. Hierarchies that came into conflict were within families because they now had to contend with new knowledge that their sons had AIDS and that they were gay as well. In many patriarchal family structures, this knowledge caused much emotional damage when families had to contend with internalized homophobia that forced family members to choose between members of the family. Conflicts were created between families and their churches. Many of the right wing churches in America forced their flock to choose between their church and their gay sons. This caused untold heartbreak for mothers and fathers who were torn between hierarchies that were intended to support people but in fact, in the face of AIDS, were causing people much emotional harm within their family hierarchy. According to Burke, these conflicts could by resolved by an exercise of purification and redemption. A study of the AIDS Quilt confirms a manifold proliferation of examples of family and
friends using the AIDS Quilt to attempt to purify their personal guilt as well as redeem themselves for the sins of rejecting their loved ones.

Utilizing Burke’s theory about how guilt is purified Rybacki and Rybacki clarify:

To resolve the guilt, two forms of ritual purification are common in the social drama, mortification and victimage. Mortification involves personal sacrifice by the guilty. The individual or group experiencing guilt makes a symbolic offering to appease society and thus restore balance to the social order. A person accused of wrongdoing acknowledges it publicly and may offer an explanation or perform some other act of contrition. (Rybacki and Rybacki 72)

The AIDS Quilts themselves and letters that accompany them are the “symbolic offerings” that are intended to purify the guilt of mothers, fathers, families, and friends individually. On a societal level, I believe the AIDS Quilt has been largely successful, turning out thousands at its public showings, because it has allowed society to attempt to redeem itself for its feelings of guilt about how AIDS sufferers have had their morality questioned because of contacting a “viral disease” that can affect anyone even those with their personal morality basically intact. The problem has not been a lack of personal morality but it has been hierarchies, such as the right wing churches, attempting to impose their personal moral beliefs onto a society, forcing it to choose between loyalty to a hierarchical structure or to the human beings in our society.

To overcome this problem of society and its members being forced to choose between hierarchies, Burke identifies a bridge that can help to accommodate them both without forcing the choice. Identification is a rhetorical strategy that Burke suggests can be used to bring people together. Rybacki and Rybacki explain, “People became symbol users to compensate for those factors of individuality that divide us from one another” (Rybacki and Rybacki 74). They then go on to explain Burke further when they say “Rhetoric
must be viewed as identification rather than persuasion because its function is to proclaim unity" (Rybacki and Rybacki 74). An example given is that though person A and person B are not identical they may have common interests and through identifying those common interests they can create "identification" between themselves that brings their interests together. Thus in Burke's dramatistic approach, using rhetoric to identify common interests symbolically creates a means of cooperation between different persons or groups. The AIDS Quilt provided just such an "identification" tool because it allowed different people to identify with one another, coming together to identify with the common humanity of the people honored and memorialized by having a personal AIDS panel included in the larger Names Project AIDS Quilt.

The Names Project AIDS Memorial Quilt works as a rhetorical device on many levels. On a personal level it is a personally crafted memorial that tells stories about people who have died during the AIDS epidemic. The power of each single panel lies first of all in its memorial function. Facing the death of a loved one asserts the enduring importance of a particular person, of a loving relationship, of intimate human connection. The loss may be that of a son or daughter, a mother or father or brother or sister or it may be a friend or lover.

Healing from loss and grief can be achieved by many strategies and I will explore in this paper the role that the Quilt has played in that. I will look at personal stories of guilt, redemption and loss and how the Quilt has played a rhetorical role to help a panel maker communicate with a departed loved one. On another level, that of cultural memory, I will explore the role that the quilt has played, thereby allowing American society to come to grips with its original response to AIDS and its losses. This original response was one of
denial and it has been suggested that the source of this denial was rooted in homophobia which allowed the many deaths attributed to AIDS to be ignored as unimportant or quite possibly as un-American. The Quilt by its design was pure Americana and according to its creator, Cleve Jones, it was intentionally so. Peter S. Hawkins, a professor of religion and literature at the Yale Divinity School, said that Jones was attempting to reinvent AIDS by transforming it by crafting a Memorial to its victims which was by design "a patchwork quilt linked to nineteenth-century sewing bees and nostalgia for a past sense of community" (Hawkins 757). The AIDS Quilt was to become a metaphor that would insure that the victims lost and memorialized in it would not be forgotten outcasts but would be honored Americans.

Additionally, I researched as many of their original speeches and communication artifacts as I could assemble. The purpose of looking at these artifacts was to investigate the personal rhetoric for clues as to how the AIDS Quilt leaders were directing their many volunteers. Much of this research was organized to support the major thesis of this paper, which is that the Names Project AIDS Memorial Quilt is the rhetorical centerpiece of a social movement that organized to fight AIDS.

Lastly, I looked at the Quilts themselves as research material. While doing my research I sought out as many original quilts as I could find as well as pictures of quilt panels and the letters that accompanied them when they were given to the Names Project for inclusion into the AIDS Quilt. My purpose in exploring these was to help me analyze the personal narrative being told by the quilt makers about the loved ones lost. I believe another rhetorical aspect to research in these letters will be hints and clues as to how the letter writer felt about the loss but also clues as to what the letter writer was going to do.
to make some social/cultural changes to change the future, with the intention to stop future loss of life through whatever means necessary.
CHAPTER 3

HOMOPHOBIA AND AIDS IN THE 80’s

This chapter examines the effect that homophobia has had on the development of AIDS public policy and on the response of a heterosexist society to AIDS. The information in this chapter will serve as background providing insight about the situation that Cleve Jones and the gay community faced as the AIDS epidemic began to intensify. Further, this chapter will argue that the Names Project AIDS Quilt fought mightily against the homophobia that delayed and interfered with what should have been a more appropriate and vigorous government response to the AIDS epidemic. Attempting to explain the AIDS Quilt’s success, Peter Hawkins says, “The Names Project has been astute in claiming some measure of an American heritage; it has used the homey associations of the patchwork quilt to domesticate AIDS, to neutralize hostility toward “high risk” gay populations by appealing to a national legacy” (Hawkins 765). The manner used by the AIDS Quilt to neutralize hostility toward the gay population was distinctly American in tradition and values. I argue in this chapter that by using traditional American values in the drive to fight homophobia to “neutralize hostility” toward homosexuality the Names Project AIDS Quilt was very successful. But to get there, I will first pursue two seemingly contradictory points.

First, homophobia, along with sexism and racism, contributed to the delayed response to the AIDS epidemic. This delayed response placed gay men at increased risk because
federal programs of prevention and research were instituted only slowly. This slow response could be contrasted with the federal government's rapid response to an outbreak of Legionnaires Disease in a Philadelphia hotel during an American Legion Convention in the summer of 1976. This contrast in government responses to different diseases that were affecting different populations indicates support for my theory that homophobia was underlying the slow response to the AIDS outbreak in America. Unfortunately, however, because of the slow response to AIDS, heterosexuals were placed at equally great risk for exposure because the programs that were developed focused primarily on gay men, obscuring the links, sexual and otherwise, that exist between gays and heterosexuals.

Looking to Burke for a theoretical explanation for this disparity in government responses to different disease outbreaks, I argue that Burke's dramatistic theory of hierarchy can explain the disparity of treatment. Legionnaires disease caused multiple deaths of war veterans, a class of citizens that are high on the scale of societal regard and recognition in America, in contrast to AIDS that caused deaths among Haitians, homosexuals, hemophiliacs, and drug users who are not socially held in such high regard in America.

Second, homophobia was not introduced into the health-care system only with the AIDS epidemic. Rather, its long-standing legacy of discrimination and exclusion had resulted in the creation of a separate health care system within the gay community, a health-care system that responded to this new crisis immediately, saving countless lives — and heterosexual lives as well — while the government-sponsored system floundered, unable to find the will or the funds to respond.

It should be noted from the start that more factors than homophobia contributed to the U.S. response to AIDS. The AIDS epidemic first struck in the early years of the Reagan
administration, an administration that not only was unsympathetic to the interests and concerns of sexual minorities but also, beginning in 1981, imposed massive cutback in two of the agencies critical to the initial response to AIDS: the National Institutes of Health and the Centers for Disease Control (Shilts 55). This information, while detailing one specific aspect of the nation's inadequate response to AIDS, should be placed in the context of a larger disabling of our nation's public health care system—a situation from which it is still recovering.

Fighting for Equality!

The status of gays in U.S. society has had profound implications for the AIDS epidemic, for the gay community's response to it and for society's response to those in the gay community affected by AIDS. That legal, political, and social context must be understood before the AIDS experience can be discussed. This disparity in status explains the reason why there have been multiple gay organizations founded in America. For example, Lambda Legal Defense and Human Rights Campaign constantly address the legal and political status of gay and lesbian Americans. And the Names Project AIDS Quilt challenged the social context with which most Americans held gays and lesbians. According to Cleve Jones, "the lesson of the AIDS Quilt is that as a society we are quite adept at creating all sorts of barriers between us...but if we are going to be successful in fighting AIDS we have to cross barriers and claim the humanity of those we have lost and say all these lives are valuable" (Jones, Cleve Personal Interview. March 17, 2001). The success of the AIDS Quilt to allow people to "cross barriers" can be explained using a
Burkean dramatistic analytical tool of “Identification” that suggests that people come
together when they identify with one another.

Gays, lesbians, and bisexuals are among the most invisible of minorities. The social,
cultural, legal, and moral stigma of identifying oneself publicly as gay, lesbian, or
bisexual keeps most gay people in the closet. But the many gay people who have come
out of the closet also remain invisible, maintaining a social marginalization, rendered
silent by media unwilling to cover our community or report on our lives for fear of
alienating their audience or because of internal biases. With the advent of AIDS, gay and
bisexual men have become somewhat more visible, but ironically lesbians, bisexuals and
women have become even more marginalized. Also on the down side, too much of the
early coverage of AIDS reinforced dangerous negative stereotypes and fears about sexual
minorities. Andriote notes: “Newsweek was the first major print outlet to report on AIDS
among others besides gay men—hemophiliacs, injection drug users, and children—the
Times and other media continued to focus almost exclusively on gay men. But the focus
on gay men had the unintended effect of perpetuating the view that they were the only
victims of the epidemic – and that AIDS was, by extension, a singularly gay problem”
(Andriote 66). So the situation that Jones attempted to correct using the AIDS Quilt as a
media tool was that “We could somehow bridge that gap of age-old prejudice… and there
was hope we could make a movement that would welcome people - men and women,
gay or straight, of every age, race, faith and background” (Jones and Dawson 108).

While the most visible people with AIDS are gay and bisexual men, lesbians have also
been affected – as people with AIDS, as advocates for political reform in the context of
AIDS, as caregivers and service providers, and as the victims of discrimination based on
the irrational association of HIV infection with all homosexuals. Lesbians have borne the political liabilities of the AIDS epidemic as they have affected the lesbian and gay community generally; they have at the same time been forced to put many political objectives on hold as the community confronts this epidemic.

The notion of a gay community – one formed on the basis of sexual orientation – is often difficult for many heterosexuals to understand. But we are indeed members of a community, despite our incredible diversity. We come from every segment of U.S. society, whether those divisions are based on class, race, gender, religion, or politics. We have essentially one thing in common: we share oppression as a minority discriminated against, demeaned, attacked, and rejected because of what is perceived as a “deviant” sexual orientation. The undertaking of the AIDS Quilt is two fold: to celebrate the incredible diversity of those who have died of AIDS, and to express the common humanity of the AIDS sufferers and not allow their sexual orientation to be their sole defining human quality.

But discrimination and oppression unite us also. In that regard, we are like many other minorities for whom shared oppression can be a defining characteristic. But there is limited value to coveting this kind of oppression. So our community has used the AIDS Quilt as a means to transform this oppression into a colorful mourning exhibit that unites us, declaring we are no longer willing to remain in the social grey of marginalization. A Burkean dramatistic analysis using “Identification” as a tool illustrates why the AIDS Quilt unites the gay community. Simply put, when the gay community visits an AIDS Quilt display, there is a little bit of every person on display
there and we all recognize, through “Identification”, ourselves and the reality that we are all in this AIDS boat together.

And as much as we are the same we are also different. Black children, for example, learn from parents, family, the church, and the community the history of the black struggle for freedom; they share with their parents similar experiences of oppression. As gay males, lesbians, and bisexuals, however, we must form our sense of our gay identity on our own. Only then can we learn to relate to a new community. We must learn this from our peers – often late in life. Each generation must build its own sense of community and history. As our community institutions grow and our visibility in society increases, that endeavor becomes easier. But every day another child or adult, learning and accepting his or her sexual orientation as different from the norm must discover a community that for many other minorities comes with birth.

And just what is the oppression that gay males, lesbians, and bisexuals face? The most explicit form is the criminalization of our sexuality by the government. Twenty-five states and the District of Columbia still have laws – so-called sodomy laws – that make certain forms of consensual adult sexual behavior illegal. Six states single out homosexual activity only. These laws are often selectively enforced against gays, deliberately used to frighten and intimidate a minority. Interestingly, here in Nevada due to the courageous leadership of state senator Lori Lipman Brown, the “sodomy” law was repealed in 1993 with the help of physicians and community AIDS Quilt activists who argued the point that the “crimes against nature” law was inhibiting the AIDS prevention work being done in Nevada. The AIDS Quilt and its activists boldly declared that we are
here, and we have lives and deaths, making the claim that the Quilt, as an art form, can transcend the law.

Sodomy laws are also used to rationalize other forms of discrimination. How can a gay person be a good parent if he or she engages in criminal acts? How can a police department hire someone gay in a state that has sodomy laws on the books? Similar questions are never asked about the sexual practices of heterosexual parents or police officers, even in the nineteen states that criminalize heterosexual sodomy. Of course, for the state to criminalize behavior that, for reasons of public health, it seeks to influence sends at best a mixed message to gays in the United States. Indeed, because of this contradiction, many health officials have joined the call for the repeal of sodomy laws as a means of promoting AIDS prevention efforts and establishing their credibility with affected communities as they did here in Nevada. Lesbian and gay Americans do not have the same privacy rights that the U.S. Constitution affords most other citizens. In June 1986, in Bowers v. Hardwick, which involved a gay man’s private consensual activity in his own home, the Supreme Court essentially wrote gays out of the constitution by upholding a Georgia sodomy law dating back to 1816. Justice White in the majority opinion said: “‘Homosexual sodomy’ was not protected, even in private, because ‘the majority of the electorate of Georgia’ believed ‘that homosexual sodomy is immoral’ ” (Fone 414). The ruling essentially asserted that no fundamental right of privacy attached to homosexual sodomy. So without constitutional protections, we are left to the whims of the states.

By 1992, in all but five states (Connecticut, Hawaii, Wisconsin, New Jersey, and Massachusetts), it is legal to discriminate against gays in employment, housing, and
public accommodations—in all those areas in which we as a society have come to accept it is improper and illegal to discriminate on the basis of race, religion, nationality, sex, age, or physical or mental ability. About eighty cities and counties have passed legislation outlawing such discrimination, a first step toward building broad-based support for and experience with such protections. Some of these communities are in states with sodomy laws, creating the irony that being homosexual is legal but that engaging in homosexual acts is not. Again, in the context of an AIDS epidemic so closely identified with a single group—gay men—this lack of protection has had profound implications.

Not only is the federal government unwilling to protect us, its policies affirmatively seek to discriminate against us—sadly, the only affirmative action gays have ever received from the federal government. The military considers (known) homosexuality to be incompatible with military service even though gay and lesbian service people have performed countless acts of bravery in action. The federal government currently allows homosexuals to serve only on the terms they would not be asked about their orientation but they must not state it—the now infamous “Don’t Ask—Don’t Tell” compromise because it is feared that mixing gays and straights in the military will undermine morale. Gay and lesbian scholar Bryne Fone says, “This law collaborates in sustaining the most oppressive kind of homophobia by creating the most oppressed kind of homosexuals: forced to be both invisible and silent” (Fone 415).

Those arguments are not at all dissimilar to those made in the 1940s against racial integration in the armed forces. The fight against AIDS in the military has been, at a minimum, confused by the denial that there could be a significant amount of homosexual
activity because that activity is forbidden. AIDS Public Policy researcher Jeffrey Levi says, “Statistics do not lie however, all branches of the armed forces have reported significant numbers of AIDS cases” (Andriote 221). Interestingly, but not surprisingly, the fear of disclosing homosexual behavior has made epidemiology among the military AIDS cases fairly unreliable; some notions of heterosexual transmission rates are therefore probably exaggerated. The willful denial of the existence of homosexual behavior makes education about the prevention of HIV transmission more difficult.

Military policy makes service people afraid to seek counseling or treatment, compounding the problem, while increasing the danger of further transmission. My good friend Paul Long was forced out of the military in 1987 due to his HIV infection, while he was in very good health, ironically serving the U.S. Navy as a corpsman tending to the health of his fellow sailors. Sadly, Paul passed away in 1989, a dispirited ex-sailor who never recovered emotionally from being driven out the military service he loved. Paul’s AIDS Quilt panel was the first one I viewed when I attended the ceremony inducting it into the larger Quilt display in Tampa, Florida, the year he died. A close examination of the many panels in an AIDS Quilt display will reveal quilt panels with many different soldier’s and sailor’s uniforms indicating that people with AIDS have died an early death after devoting a portion of their lives to the service of their country.

Military service is not the only national service that is prohibited because of the discrimination lesbians and gays suffer. National security agencies either automatically deny security clearances to lesbians and gays or subject them to a higher level of scrutiny – on the basis of the (false) notion that homosexuals are more susceptible to blackmail than are heterosexuals. Bryne Fone notes a federal government document from 1950
titled “Employment of Homosexuals and Other Sex Perverts in Government” that
“labeled sexual perverts today as dangerous security risks and demanded strict control
and careful screening to keep them off the government payroll.” Fone further explains
the Senate committee issuing the report noted “The lack of emotional stability which is
found in most sex perverts and the weakness of their moral fibre makes them susceptible
to the blandishments of foreign espionage agents” and “easy prey to blackmailers.”
Ironically Fone concludes, “Most, if not all, sex scandals in which national security has
been compromised have, however, involved heterosexuals” (Fone 391). So I maintain
that rather than singling out one group, a single standard ought to be applied to all.

Congress has also imposed a ban on immigration by those infected with HIV, at the
behest of Senator Jesse Helms. This law is counter to international public health
standards, including the policies of the World Health Organization. It is even opposed by
the Public Health Service. HIV is communicable through unprotected sexual activity; the
mere presence of foreigners with HIV creates no public health threat. The ban incensed
representatives to the International AIDS Conference in San Francisco in June 1990, and
many mainstream international and U.S. organizations boycotted the event. (Andriote
249) This is but one example of the fear and hysteria surrounding AIDS resulting in
congressional involvement in public health policy-making. As part of the 1990
immigration reform law Congress restored to Secretary of Health and Human Services
Louis Sullivan the power to remove HIV from the list of excludable conditions. But in
1991, President Bush refused to take Sullivan’s suggestion to remove HIV from this list.
Because of Bush’s blatantly discriminatory policy, the Harvard AIDS Institute [the
sponsor of the 1992 International AIDS conference] carried through on its threat to
transfer the conference outside the United States from Boston to Amsterdam.

(Blumenfeld 335)

These federal government official policies have reflected society's irrational hatred and fear of homosexuality. So it is not surprising that so many people in the United States misunderstand and are intolerant of gay people when they live in a culture where many mainstream religions condemn homosexuality and Far Right fundamentalists make their living promoting antigay bigotry. The Moral Majority while lobbying against federal AIDS funding in 1982 said: “If the medical community thinks that a new drug is what is needed to combat these diseases, it is deluding itself. There is a price to pay for immorality and immoral behavior” (Patton, Sex and Germs 96).

A little more that a year later they said:

Why should taxpayers have to spend money to cure diseases that don't have to start in the first place? Let's help the drug users who want to be helped and the Haitian people. But let's let the homosexual community do its own research. Why should the American taxpayers have to bail out these perverted people. (Patton, Sex and Germs 97)

The toll of this type of oppression is documented by a startling increase in violence against gays, lesbians, and bisexuals over the last several years. According to FBI Hate Crimes Statistics, from 1991-2000, the percentage of crimes based upon sexual orientation has increased from 8.9% to 16.1%. This incredible increase in violence during the AIDS epidemic is significant because it indicates that people play out their own fears about AIDS against the one group that is so visibly identified with the epidemic.

Another aspect of the discrimination under which gay people live is rejection of our parents and families from whom most of us seek comfort, support, and love. While many
families are supportive - look to the growing number of Parents and Friends of Lesbians and Gays (PFLAG) chapters around the country – far too many reject their gay children. A quilt panel pictured in The Quilt - Stories from the Names Project illustrates the sadness this experience can cause. This standard panel is decorated scantily with various identifiers such as a rainbow flag and Jewish Star of David, a car and a flower bouquet and includes this descriptive text “I have decorated this banner to honor my bother. Our parents did not want his name used publicly. The omission of his name represents the fear of oppression that AIDS victims and their families feel”(Ruskin 79).

And finally, the problem of suicide is extensive because of emotional difficulties that gays and lesbians experience in our society. The spiraling rate of suicide among gay youths attests to that difficulty. Even acknowledging that spiraling suicide rate as a serious problem is, however, controversial in the current political climate. When a National Institute of Mental Health Study suggested that antigay attitudes might be the cause of the high suicide rates among young gays and lesbians, pressure from California Congressman William Dannemeyer, one of the leading congressional homophobes, caused Louis Sullivan to call for a review of the study. Sullivan issued a statement distancing himself from any definition of family that included homosexuality. (Blumenfeld 333) Sullivan, of course, headed the agency charged with the fight against AIDS. And he wondered why the gay community was angry and frustrated!

I have detailed the status of gay men and lesbians in U.S. society at such length because of the profound effect that status has on the public health problems posed by AIDS. I have also meant to show why the traditional approach taken by the public health
community has both faced resistance and required adjustment when applied to the AIDS epidemic.

Late Out Of The Gate?

While the delayed response to the AIDS epidemic by the federal government has been well documented, the causes of that delayed response are various. Was it a result of overt homophobia? Or can it simply be attributed to a public health system crippled by Reagan administration budget cuts?

I think the problem must be assessed at different levels. There is no doubt that the policymakers at the White House, most notably domestic policy advisor Gary Bauer, introduced elements of overt hostility toward gays into the debate. (Andriote 69) But such overt hostility was not a factor at the Public Health Service. Indeed, many PHS employees turned out to be sympathetic toward and supportive of gays. Since much of the initial response to AIDS was channeled through existing PHS programs, why then the delay? I think the answer is ignorance. While the responsible officials were not necessarily homophobic, they knew nothing about the gay community. Randy Shilts notes that in the first Public Health Service pronouncements on AIDS included risk reduction guidelines that only offered two sentences of guidance to gay men who were eager to avoid the strange new disease, despite reams of data collected in the still-unpublished case control study. (Shilts 243) The gay community did not even exist in the minds of all too many public health officials until the epidemic forced recognition. Only minimal lines of communication linked the gay community and the public health system, lines certainly not strong enough to recognize the growing problem or to activate the
system. And because there were few established ties, and in their place a legacy of distrust, it was hard to establish stronger ties quickly. Without such ties, the government developed no sense of urgency, all budgetary constraints aside. Inertia prevailed in a system already unable to keep up with current public health demands. As a result, thousands of lives were lost.

Help Yourself Or Die!

Without an appropriate government response, the gay community had to turn to itself to provide the initial, and continuing, response to the AIDS epidemic. Oppression has served us well in one regard, probably saving tens of thousands of lives in the process. Because of the suspicion with which society, government, and the medical establishment viewed the gay community and we they, a gay health movement took hold in the mid to late 1970s, inspired in large part by the women’s health-care empowerment movement beginning in the 1960s. Androite explains that “It was also fortunate for gay men that lesbians, steeped in the feminist politics of the late sixties and early seventies, understood the connection between personal health, the power dynamics of health care, and one’s position in society” (Androite 41). And further, Androite explains that AIDS clinics got an early boost because “Gay men working in the health care profession with lesbian colleagues were able to tap the existing network of community-based gay clinics to create momentum within the health care professions to consider the health of gay men and lesbians as an issue worthy of serious attention” (Androite 41).

In many of the larger cities across the nation, gay men had formed gay health clinics as early as the late 1960s, not trusting the medical establishment to treat them for sexually
transmitted diseases. In the early 1980s, the gay community turned to these groups to generate the original AIDS service organizations. Providing care and AIDS education, these organizations saved the government from its own inaction, and they continue to form the basis for the local response to AIDS. They are a model of Reagan Republican voluntarism or George Bush's "thousand points of light." But they are also being asked to carry a burden far in excess of what would ordinarily be asked of the private, voluntary sector.

Normally, volunteer organizations receive substantial government assistance when confronting a new problem as overwhelming as the AIDS epidemic. Yet no federal funding for AIDS prevention was available until 1984, when Congress created a program of minimal assistance to community-based organizations funded by the U.S. Conference of Mayors (Androite 139). Several years into the epidemic, even sympathetic members of the Public Health Service recognized that the federal government was providing inadequate assistance to gay organizations fighting AIDS. Through some imaginative financing – conceived by a Reagan appointee but carried in Congress by California Democrat Ed Roybal – funds were funneled to these organizations through the Conference of Mayors ($150,000 the first year, a sum that grew over time). Ultimately, community-based prevention programs were funded directly (Shilts 471). Because of homophobia, such funding came only after a delay and probably at a lower level than would have been granted to a more politically acceptable cause.

The funding of AIDS-related service and prevention programs by local governments has followed a similar pattern. Community-based organizations were at first allowed to struggle on alone. The Names Project AIDS Quilt provided itself as a fundraising tool
for community-based AIDS service organizations since its creation in 1987 because no other sources of major funding were readily available. During 1988, from March to July, the Names Project volunteers took the Quilt on a 21 city national tour, during which it raised $500,000 for hundreds of local AIDS service agencies (Jones 253). But things would change eventually when several years into the epidemic, as voters began to demand that the government do something about the epidemic, local politicians began to fund AIDS service organizations. Enjoying the best of both worlds, these politicians could provide the mandated AIDS-related services while sidestepping the social and political controversy necessarily involved had those services been introduced in existing public health programs.

There is a certain logic to this. The gay community itself had argued that prevention efforts should be targeted and that those affected would deliver the message more effectively, that gays would accept suggestions about changes in sexual practices more readily from other gays than from an employee of a government that still endorsed sodomy laws. But these gay organizations were being asked to take on the entire AIDS prevention effort, not just that focused on the gay community, and were given limited funds to do so. As a result, the needs of many in the heterosexual community – those at risk because of sexual activity and those at risk because of intravenous drug use – were neglected. So were the needs of many segments of the gay community itself. But this was addressed with the help of the AIDS Quilt when many of the gay-based AIDS organizations using the Names Project AIDS Quilt drew their volunteers from the white middle class, volunteers who at first seemed either unwilling or unable to speak to the diverse gay population. The AIDS Quilt’s ultimate contribution was that it allowed
communities to come together as one, concerned with the health and well being of all Americans and it forced our society to transcend its fear with the many open public AIDS Quilt displays. This coming together is explained using the Burkean dramatistic “Identification” tool to illustrate that people, though different, do find similarities to identify with when given the opportunity.

Politics and Public Health!

Throughout the AIDS epidemic, the Far Right has argued that the gay community has used the attention and access to the political system generated by the crisis to further its civil rights agenda, placing politics above public health. I would argue that it is the other way around, that throughout the epidemic the Far Right has imposed its own political agenda on the nation by fighting funding for gay community-based organizations or by trying to restrict the content of AIDS education efforts. Andriote says: “As if fear alone wasn’t challenging enough, those in the suddenly energized so-called Christian right – emboldened by their access to the highest levels of government – jumped on AIDS as if it was manna from heaven. They thrived on the fear and hatred of gay people that, for them, seemed a justifiable exception to Jesus’ commands to love others and to care for the sick” (Andriote 47).

The gay community in contrast has never opposed measures that it thought might stop the spread of AIDS, for it is our own lives that are at risk. Our position has been and is much more complex. No attempt to control the spread of disease can be successful without the cooperation of those affected. That cooperation can be based only on trust, but there can be no trust without understanding. Health-care policies cannot be devised
without taking into account the social factors governing the lives of the people they affect. In other words, good public health requires a healthy respect for civil rights. Cindy Patton explains: “Privacy and civil rights law has tended, under the influence of the new left, feminist, and lesbian/gay movements, to become more inclusive, to extend to categories of people or activities that were not necessarily originally enumerated” (Patton, Sex and Germs 82). The gay and lesbian community has provided leadership with regard to public health in America and this has benefited all its citizens regardless of their sexual orientation.

To insure all people have access to public health, the gay community has managed to convince the overwhelming majority of the public health community that the issues of confidentiality and nondiscrimination had to be addressed before an effective public health strategy to fight the spread of AIDS could be implemented. In the historical context of officially sanctioned discrimination, it is particularly impressive that the gay community was so willing to cooperate with the public health community. We often asked our challengers to put themselves in our shoes, asking them: Would you come forward to be tested for HIV or participate in a prevention program if by doing so you would publicly proclaim yourself as gay and at risk – thereby leaving yourself open to losing your job, custody of your children, or your home? Would you speak frankly to government epidemiologists if the manner in which you contracted AIDS were a felony? Would you cooperate with a Public Health Service that worked with the government to deny your fellow gay men the right to travel and emigrate? Would you be responsive to public health education campaigns that condemn who you are, telling you to change your...
sexuality in the name of the public good, as so many of the government's early publicity efforts did?

Looking at it from this perspective, it is amazing that, despite the risks, gays have answered yes to these questions, but such a response was necessary to halt the spread of HIV. Nevertheless, the battle against AIDS would have been easier and more effective had it not been necessary first to fight homophobia and the discrimination that has resulted. This is where the civil rights agenda and the public health agenda merge: the society that now so fears AIDS is paying the price of generations of discrimination against gays by having created conditions that do not encourage those most affected to participate in public health measures.

Despite the clear link between antigay discrimination and HIV-related discrimination, despite the link between anti-gay policies and attitudes and the fact that many homosexually active men at risk are still driven underground by the fear of discrimination, there has been little progress in the fight for greater civil rights protections for lesbians and gay men as a result of the AIDS crisis. This runs counter to the image that the Far Right puts out, but it is true. By 2002, twenty years into the AIDS epidemic, only four states, Massachusetts, Connecticut, New Jersey, and Hawaii, have been added to the list of those outlawing discrimination based on sexual orientation. Few states have repealed their sodomy laws – though many in the public health community argue that they impede frank discussion of risk in prevention and epidemiology programs. While many local jurisdictions and the U.S. Congress have approved protection against discrimination based on HIV status, and in some cases, perceived risk for HIV, the situation remains that gay and bisexual men are protected from
discrimination only if they are infected with HIV. Non-infected gay and bisexual men are afforded no such protection.

Some public health measures meant to combat the spread of AIDS could not be implemented until nondiscrimination and confidentiality were guaranteed. Confronting the issues, however, meant diverting attention from preventative efforts. Those efforts were delayed, and that delay killed. And it increased the risk faced by all people in this country who might be exposed to HIV.

What to Fear: Sex or Homosexuals?

HIV is transmitted primarily through unprotected sexual activity. Even as more and more cases of HIV infection can be attributed to intravenous drug use, sexual transmission – between drug users and their partners – continues to play a major role in the spread of AIDS. U.S. society has never dealt well with sexuality in general, let alone homosexuality. The history of sexually transmitted disease control in the United States is one of repression rather than one of confronting the realities of sexual expression.

Repressive attitudes obviously hinder efforts to prevent an infection that is sexually transmitted, especially when the only truly effective preventative measure is education about behavior change. But at the outset of the epidemic, AIDS struck gay men almost exclusively. Is it therefore sexphobia or homophobia that has prevented an appropriate response? Put differently, could we have expected any better had HIV affected heterosexuals almost exclusively? The research conducted for this study suggests the answer to that question is yes, most certainly heterosexuals would have been treated much better.
Certainly, efforts at education within the gay community have prompted some of the most virulent homophobic attacks to date. Nevertheless, the gay community has developed model programs aimed at effecting behavior change. There is almost universal agreement in the public health community that the results among gay men have been dramatic, often gauged by dramatically declining rates of sexually transmitted diseases (rates that have recently skyrocketed among certain segments of the heterosexual population). Safer sex is commonplace in many gay circles, a fundamental change in behavior that few experts would have believed possible.

The programs that have accomplished so much have been frank, gay positive, and sex positive, and they have usually not had government funding. Government officials fear those programs that are most effective because they might be seen as promoting homosexuality. Perhaps the most infamous expression of that point of view came in 1987 from Senator Jesse Helms of North Carolina, who proposed an amendment to an AIDS appropriations bill that would prohibit federal funding of materials that “promote or encourage...homosexual sexual activities” (Patton, Inventing AIDS, 40).

Helm’s amendment passed by a vote of ninety-six to two. The amendment has since been rewritten, more neutral language now linking any discussion of sexuality to the promotion of risk reduction, but its chilling impact is still felt today. The overwhelming initial vote, and the great struggle necessary to overcome opposition, stems from Helm’s uncanny ability to turn AIDS discussion into a condemnation of homosexuality, tapping the greatest personal and political fears of many members of Congress. In this instance, he used a relatively explicit campaign launched by the New York based Gay Men’s Health Crisis (GMHC), including their publication of “safe sex comics,” in his attack on
gay-positive safer-sex education. Indeed, Helms and several other right-wing members of Congress seemed to derive a particularly strange pleasure from detailing allegedly common sexual practices among gay men. Helms, however, omitted two facts in the debate: the GMHC materials were not published with federal dollars, and such material has been demonstrated to be the most effective means of inducing changes in behavior.

The effects of the Helms amendment went well beyond the gay community. All explicit safer-sex education is threatened when only the promotion of abstinence is politically safe. More broadly however, and more dangerous, the approach Helms took—that HIV is spread by homosexuals pursuing pleasure with abandon and without considering the risk posed to the rest of society—makes heterosexuals feel safe, feel that they are not at risk. So much of the debate about HIV that is homophobic creates a sense of “otherness” about those infected, allowing people to rationalize not dealing with their own risk of exposure to HIV. This “otherness” or the belief that others are only susceptible to AIDS is the primary notion that the AIDS Quilt was attempting to correct. When it comes to AIDS there are “no binary opposites of us and them,” as Sontag notes such a position is dangerous because a virus knows no bounds and all humans are susceptible to infection.

What Did We Learn?

If there is an overriding lesson to be learned from the gay community’s experience with the AIDS epidemic—and how society’s attitudes toward gays have driven so much that is wrong with the national response to the epidemic—it is that discrimination kills both those who are discriminated against and those discrimination is meant to protect.
Delaying or hampering a response to what was perceived as simply a problem of the homosexuals in fact harmed many heterosexuals. The extent of the problem was underplayed; the likelihood to heterosexual spread was minimized. And while the rate of infection has not risen as rapidly among heterosexuals in the United States as among gay men, it is rising steadily. Most people in the United States have not overcome their sense of "otherness" with this crisis. First only gay and bisexual men were affected and the majority of society could breathe a sign of relief. Now it is known that injection drug users and their partners are affected, most of whom are poor and black or Hispanic, and the majority can still breathe easily. But this false sense of security cannot continue.

Never before has a sexually transmitted disease remained confined to one group; there is no reason to believe HIV will be the exception. Many heterosexuals – forewarned as gay men were not – have squandered the extra time given them.

Public health officials have learned some important lessons working with the gay community. They have come to respect the gay community's work combating the AIDS crisis, and they now understand that cooperative efforts can be quite successful. Mistakes continue to be made, however. The gay community was assumed to be monolithic, and minority gays were therefore neglected. No account was taken of the fact that intravenous drug users might be just as mistrustful of and alienated from the public health system as gay men once were. No one remembers that community run programs are the most effective.

The conclusion to be drawn is that discrimination and prejudice are legacies that hamper public health efforts and place the entire population at greater risk. Society is paying for its legacy of homophobia – not only in gay lives lost but also in heterosexual
lives placed at risk and social institutions overwhelmed with their existence jeopardized. There is still time to turn this sad experience around – if in the future our society takes a page out of the Names Project AIDS Quilt mission statement and endeavors "To use the AIDS Memorial Quilt to bring an end to AIDS" so that we can prevent the future for many other people from looking like the past of some who have come before.
CHAPTER 4

AIDS – MY COMMUNITY – AND ME

AIDS Makes Its Entrance

This chapter is composed of three distinct parts, my personal memoirs, the contribution of my interviewed subjects, and the theories of multiple AIDS Quilt researchers. My intention in this chapter is to tell a story of AIDS from differing perspectives while tying them together with theories that prove my thesis that the AIDS Quilt is the rhetorical centerpiece of an AIDS movement in America, a movement that brought people together powerfully and in ways that made a huge difference to all in society, especially those affected directly by AIDS.

My personal memoirs are random observations that have taken place since 1982 and they are in the context of my overall experience with AIDS. It has been just over twenty years since the beginning of the AIDS epidemic in America and much has changed during this time with regard to how those who have become infected with the HIV virus are treated. But what has changed most is the way in which people who we know are HIV infected or have developed AIDS after living with the virus for many years are treated. The AIDS Quilt has contributed much to claim the humanity of those who have died from AIDS by not allowing them to be mischaracterized as only “sexual outlaws” or “social pariahs” to be shunned and disregarded, as was the case at the outset of the AIDS epidemic in America in the early 1980’s.
My first conscious memory associated with AIDS was shared with my father in the fall of 1982 when we watched as Dan Rather of CBS News announced a new "gay cancer" that was being detected in San Francisco and New York. Dad and I watched the news together during this visit home to Holley, New York, which was from Labor Day to New Years Day. In our silence, my father and I both understood what this could mean to our family. Epidemics are seldom confined by geographic borders, which meant that my new home town of Houston, Texas, which has a large gay community, could soon become the next American city where the disease was going to be detected.

As 1983 was ushered in, I flew back to Houston to put my life back together after a brief respite under my father's watchful eye. During all my adult years, Dad and I never talked about my gay orientation but I always knew, he was on to me, and I anticipated what the conversation would entail when Dad initiated it. With a little bit of regret, I know today that that conversation should we have ever had it would have gone just fine. My father's love was omnipresent, always there no matter the personal or family circumstances. Dad and I would have talked about my gay orientation at some point I am sure, but our busy lives put it off as I prepared to go back to Houston on New Years Day 1983. As he had done many times before, my father took me to the airport for my flight back to Houston. As Dad and I were saying goodbye this time, it was different from all those times we said goodbye before. The hug was a little bit longer and harder and when he looked me in the eye and said, "now you take care of yourself," a wave of knowing came over me. With that came peaceful acceptance of my father's unconditional love of me no matter my gay orientation.
After our goodbyes, I boarded the airplane and settled into my seat and as I did this the events of the past four months overwhelmed me. Questions and thoughts flooded my mind. Though I had not had the “gay” conversation, I knew my father understood and I was loved as always before. In my father’s parting words I found strength and resolve to “take care of myself” in new ways I had not imagined nor believed necessary before. My mind then raced back four months to the night Dad and I watched Dan Rather announce the “gay cancer” news. In my heart I knew that if this “gay cancer” was real, it was currently spreading in Houston too. The next stage of my life was a short 3-hour plane ride away and I was on my way with a slight dread of uncertainly with a new “gay cancer” spreading in my home town but I was personally strengthened knowing the unconditional love and support of my family was behind me.

Upon returning to Houston my “gay” life returned to normal for the most part. I got a job at a telecommunications company that eventually relocated me to Dallas but in the meantime I socialized using basically two outlets, bars and bowling. We were beginning to hear more and more about the “gay cancer.” Along the way the unspecific “gay cancer” became Gay Related Immune Deficiency (GRID) and then Acquired Immune Deficiency Syndrome (AIDS) when the scientists began to realize that the disease could strike anyone and was not necessarily “gay” related. During the early 1980’s a sense of dread overtook the gay community as more and more people got mysteriously ill and then passed away quickly. By 1985, after I had relocated to Dallas where I suffered my first loss of a close friend to AIDS, fear was palpable in the air but it wasn’t talked about much. The old saying “whistling through the graveyard” comes to mind because while
we were going about our business as usual at that time we knew something extraordinary was killing our friends but we didn’t know what it was or how to stop it.

The feeling of anxiety was omnipresent wherever gay people gathered, but for the most part, because a direct cause to the disease had not been identified as yet, it was possible to remain somewhat detached from the dreadful feelings associated with the fear of a new life threatening disease. But the detachment was not to last and AIDS got personal with me in June of 1985 when I lost my first close friend, Michael Steiniger. The following tribute was written by me and published in the local gay TWT – This Week in Texas magazine that June. In its entirety it reads:

After picking up your current TWT[Vol.11,No.11] at a local Dallas bar. as is my custom on Friday nights, I happened to glance at your recently enlarged obituary column that told of the recent death of a friend, Mike Steiniger. While I was walking down the street that night, on a beautiful Friday evening, I found myself slapping the TWT angrily against a light pole and crying over Michael’s death. I had known about Mike’s illness, because I had kept in contact with my lover after I had moved to Dallas from Houston in 1983. What brought on this fit of emotion was the unfairness of the disease called AIDS and its insensitivity to the people that it chooses to strike. Mike was no different than I in many ways that I can determine. He was fun loving, kind, and caring and had a sincere liking for people. Anyone who knew Mike during their association with the MSA Bowling League can attest to his fairness and attention to his people’s needs. His intended purpose always was to take care of whatever needed to be done and to leave any concerned person satisfied that their problem was in good hands. I will miss Michael as I have missed him since I left Houston and the MSA Bowling League two years ago; and I feel that Houston will miss Michael more, because the loss of any human of that quality, no matter by what cause, is sincerely a loss.

So that’s how things were going for me in the mid 1980’s. Just awful. And no matter how many letters to the editor I could write it would not help stop the dreadful
uncertainty that was all around. I was losing friends, others around the country were losing their friends as well. A first rate health crisis was gaining momentum causing thousands of deaths all across the country as well as around the world. The following is an account of how four others coped with the new reality that was upon us.

My Community

AIDS was becoming the major health care crisis of the century causing multiple unexplained deaths and it was beginning to affect people in all communities throughout America in the 1980's. This section of this paper will detail how others were responding to the new reality that AIDS was dictating to us. For this part of the study I conducted four interviews with principals who have much experience and knowledge regarding the history of the Quilt. The interviews were with Names Project AIDS Quilt AIDS founder Cleve Jones, Gert McMullin, the production coordinator of the Names Project AIDS Quilt since its inception in 1987, Kay Valerdo, Co-chair of the Las Vegas Chapter of the Names Project during the late 1980's and early 1990's, and Matt Kaminski, the receptionist at the Names Project office in San Francisco from 1999 to 2001.

The first interview I conducted was with Cleve Jones. This interview was conducted on March 17, 2001, in Palm Springs, California, and it primarily focused on the AIDS Quilt as a social movement tool and how it was used to redefine the AIDS epidemic. During the interview, we discussed his intention to infuse and change the political landscape of how America's power brokers were dealing with the ongoing AIDS epidemic and its human losses. Particular questions I asked Mr. Jones concerned issues like the AIDS Quilt as background for social drama, the stages of life of the AIDS Quilt.
as a social movement artifact, and the personal history of the AIDS Quilt and the reasons for its success.

Cleve Jones – Names Project AIDS Quilt Founder

Leland M. Griffin in his article, “A Dramatistic Theory of the Rhetoric of Movements,” includes in his social movement definition that “all movements are essentially moral – striving for salvation, perfection, the good” (Griffin 456 ). I explore other criteria to support my assertion that the AIDS quilt is the rhetorical centerpiece of the AIDS movement in greater detail, but for now I will contend that Cleve Jones met and raised his work to movement status when he delivered a speech on October 8, 1988, on the steps of the Lincoln Memorial saying:

History will record that in the last quarter of the twentieth century a new and deadly virus emerged, and that in the one nation on earth with the resources, knowledge, and institutions to respond to the new epidemic failed to do so. History will further record that our nation’s failure was the result of ignorance, prejudice, greed, and fear. Not in the Heartlands of America, but in the Oval Office and the halls of Congress. (Hawkins, 1993, P.760)

During my conversation with Jones, we discussed his personal reasons for its creation and, in particular, the emotional backdrop that was provided in the Castro area of San Francisco during the beginnings of the AIDS epidemic. To my question of what were the emotions going on in the city at that time, Jones replied, “Certainly for me and my friends, the predominate emotions were fear, hate, and despair. Fear of getting sick and dying and hatred for the administration and a heterosexual world that was ignoring what was happening. And despair that there just didn’t seem to be any hope.” (Jones, Cleve. Personal Interview. March 17, 2001) This bleak analysis of the state of mind of many
people in the gay community suggests a primary “social movement” requirement was being met during that time period. Griffith says that some people in a society during the genesis stage of a social movement will notice an “imperfection” in the existing order. Stewart, Smith and Denton further explain that these “imperfections” may be institutional or “they may be a threat to the social order, values or environment ... and likely to grow more severe unless appropriate institutions address it quickly and in earnest” (Stewart, Smith and Denton 72). The institutions of American government were not responding to the AIDS epidemic that was killing thousands of people and something needed to be done that would help change that.

Thus the AIDS Quilt became a way of visibly invoking the presence of those who had died by claiming a context in which to express the significance of those deaths by visibly resisting the forces that make invisible the lives of those at risk from AIDS.

Explaining his idea of the Quilt and how he thought it would help Jones said:

I saw it as a media tool, an organizing tool. First and foremost, I saw it as a visual symbol that could be used by the media to illustrate the enormity of what was happening and to reveal the lives that were disappearing. So there was the quilt as visible evidence and I saw it as an organizing tool a way to break through the silence to get people to speak out. And also I thought of the Quilt as this sort of “moral statement” in terms of value of the lives represented and claiming the value of those lives. (Jones, Cleve. Personal Interview. March 17, 2001)

When I followed up his assessment of the psychological state of the Castro and its inhabitants with a question about what Jones thought was needed he said:

I thought of the Quilt very much in the early days and even before it existed I was obsessed with the idea of evidence. You know that I could live on Castro Street at this epicenter that somebody
could walk down that same street and not have the slightest awareness of what we were experiencing because there was no evidence. (Jones, Cleve Personal Interview. March 17, 2001)

According to social movement philosopher Eric Hoffer, another component that is key to social movement is that there are people pushing back against the movement organizers and participants. Hoffer explains "imperceptibly the man/woman of words undermines established institutions, discredits those in power, weakens prevailing beliefs and loyalties, and sets the stage for the rise of the mass movement" by intention or accident (Hoffer 20). My sense is that there was a lot of pushing going on in the gay community about the different AIDS movements, ACT-Up was a part of it, the Quilt was a part of it. The question I posed to Jones regarding this "pushing back" was what it was like? Jones, the natural born activist replied instinctively "Oh it was fun."

Jones went on to explain:

Because it reveals a difficulty within AIDS movements. Who is the enemy? The virus is the enemy but you can't meet the virus on the street and beat it up. You can't picket its house. You can't assassinate it, you can't vote it out of office, you can't do any of the things that people have used historically against their human enemies. (Jones, Cleve Personal Interview. March 17, 2001)

This answer illuminates a dilemma because, though the virus was the real enemy that was killing thousands of gay Americans, the government's lack of any perceptible response to the rising epidemic compounded the predicament and it was believed by many that the lack of any response to the AIDS epidemic was furthering its spread and dooming many in the community.

Regarding the government's lack of a response Jones says:

Then there was the perception of course that we were up against and I think an accurate perception that we were up against a cold and unfeeling President, two Presidents, a Congress which was
failing to act. Look at how much attention was paid to just getting President Reagan to just say the word AIDS rather than specific policy issues. There was enormous resistance to any sort of action. Dr. Koop created enormous controversy when he mailed information to every household.

(Jones, Cleve. Personal Interview. March 17, 2001)

When I asked about specific government inaction that the Quilt organizers may have encountered Jones laughed and said:

We were denied permits by the National Park Service but what I liked about it was when it gave people a specific target. In our case her name was Sandra, she was the gran pubaa over national Park Service and we used it. And we used it as a vehicle for organizing. I called in a staff/volunteer meeting I told everyone to drop everything they were doing. This person was going to call every member of every one of our chapters and host committees and volunteer and we were going to organize a letter writing and call in campaign to jam the switchboard in the Capital and the National Park Service. (Jones, Cleve. Personal Interview. March 17, 2001)

And proudly Jones concluded, “U.S. Representatives said they got more calls on this issue than they had received on any issue ever. It was about a permit but it was about AIDS, it was about people speaking out about the AIDS Quilt and we succeeded because many people obviously were heard.”

Referring to the nexus between the Quilt and morality Jones said: “I certainly saw it as a moral statement that we were taking the Quilt to the capital” (Jones, Cleve Personal Interview. March 17, 2001). Noting his belief that the Quilt as a social movement artifact was traditional in its approach to AIDS activism, Jones said:

If you study the great nonviolent civil disobedience movement’s leaders, they say it will only work when they claim and stake out the moral high-ground and they are able to make that legitimate claim through their suffering really. They make that claim and hold onto it. By enduring the suffering and responding with dignity rather than violence, with love rather than hate.
So the Quilt was, I felt, right in that tradition though I was never prepared for the spiritual power of it. (Jones, Cleve Personal Interview. March 17, 2001)

The moral breakdown of America’s response to AIDS caused others, rather than the traditional institutions, to respond. So when the Names Project took the quilt to Washington to lay at the foot of these non-responsive institutions of power it acted as a wake-up call for these institutions. Nonviolent activism in the form of a memorial Quilt, honoring the dead from a disease that no one wanted to talk about, shamed the institutions into responding to the unfolding epidemic with resources to fight back. The lovers, families, and friends of the people who had died from AIDS had come together in Washington, D.C., bearing the evidence of their love and commitment to those they had lost. They came to mourn their lost loved ones but they also came to make a moral statement that the status quo response to this new epidemic was not acceptable.

While discussing the connection between the Quilt, healing, grief, and activism, Jones said, “You know healing for me was not the priority then, the priority was not for people to heal their grief, we were many steps from that. First they had to express their grief and their fucking outrage at what was happening” (Jones, Cleve Personal Interview. March 17, 2001).

Jones’ response fits perfectly in accordance with Kenneth Burke’s dramatistic theories because the expressions of “grief and outrage” are dramatic emotions that imply the presence of conflict in the social order. Stewart, Smith, and Denton note that:

> Emotions are articulated through dramatic actions, issues, and statements. Imagination creates a new order, governmental system, or social utopia. In simple terms, therefore, when division in society is so great that symbols no longer possess common meanings, people will turn to leaders who will create new symbols. When symbols can no longer transcend differences among people, conflict can only be resolved through violence. (Stewart Smith and Denton 173)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
So the AIDS quilt became a new symbol created by the imagination of a young AIDS activist that reflected America's compassionate embrace of people who had died from this new disease that was wrecking havoc throughout the land. The AIDS Quilt fought fear and apathy by showing, for all to see, the humanity of each person who was honored in an AIDS quilt panel.

The spiritual or sacred quality of the AIDS Quilt is frequently mentioned when the Quilt is discussed. Jones referred to the “pure spiritual power” that was revealed to him at the first Washington display. Valerdo noticed something similar when she said, “it’s almost as...I don’t know why but it is such a spiritual feeling and a kind of reverence to touching the fabric. I don’t know what it is but it is just amazing.” Kimberly Rae Connor suggests this sacred or spiritual quality is associated with the boundaries that AIDS creates and imposes on the lives of those afflicted and affected by AIDS. Using the metaphor of space, she explains how the Quilt creates a “Common Geography of the Mind” that invites the “voluntary sharing of experience in the most complete and only available way possible – through spiritual engagement and empathetic identification” (Connor 48). To me, this sharing of experience that creates a “Common Geography of the Mind” seems firmly rooted in Burke’s Dramatist theory of Identification, as a primary source of creating common bonds that propel us to spiritually come together to identify with the common humanity of those memorialized in the Names Project AIDS Quilt.

Kay Valerdo – Las Vegas Names Project Chapter Organizer

The next interview conducted for this thesis was with Kay and Chuck Valerdo and their daughter Michelle. It took place on May 24, 2001, at their home in Las Vegas,
Nevada. During this interview Kay provided me many insights that proved helpful as I constructed the theoretical foundations to support my thesis. Kay had been the Co-chair of the Las Vegas, Nevada Chapter of the Names Project during the late 1980’s and early 1990’s and she has been a friend of mine for many years. Sadly, she lost her brother to AIDS in the late 1980’s and that’s when she began her personal involvement with the Names Project AIDS Quilt. During our friendship, I have personally witnessed her commitment to the AIDS Quilt as she sought the healing and closure associated with it. Though I did not know Kay very well at that time, she did accompany me and my partner to Washington, D.C., in October 1992 for a national Names Project AIDS Quilt display. This was the first time I had attended a national Quilt display and together with her support and assistance, she helped me induct my Quilt panel memorializing eight friends I had recently lost to the epidemic, into the Names Project AIDS Quilt.

During our interview, I asked Kay a question about spirituality and her experience of the AIDS quilt. In her response, she talked about a profound spiritual feeling that the Quilt emanates to all in its presence when she said:

And it is...its almost as...I don’t really know why but it is such a spiritual feeling and a kind of reverence to touching the fabric. I don’t know what it is about it but it is just amazing...I feel like I know what every single person feels like. It unites in a way that is so profound. I don’t know why but it does. (Valerdo Interview May 21, 2001)

Kimberly Rae Connor explains this profound “spirituality” happens because of a sharing of experience through “spiritual engagement and empathetic identification” (Connor 48).

Connor then goes on to explain that “Larger implications of this notion of a common geography and its spiritual potential take on, not just a textual, but an actual presence in the Names Project AIDS Memorial Quilt” (Connor 48). The AIDS Quilt therefore gives
life to the "spirituality" of the lives that are inherent in its creation and it does so through "Identification." Burke's dramatist theory becomes significant here in Connor's explanations and she builds upon that when she says, "The AIDS Quilt represents a ritual transformation of profane space into sacred space and carries an additional authority because its landscape includes not just gay men but all those who have been afflicted or affected by AIDS...demonstrating an imaginative ability to landscape the geography with meaning" (Connor 49-50). Hence a visit to the AIDS Quilt allows people to transcend their own life and take meaning from another's in the course of a visit to an AIDS Quilt display. But finding the "meaning of life" is not the only result elicited from visitors and volunteers upon a visit to the AIDS quilt.

A fundamental power of the Quilt to transform and heal is illustrated by a story Kay told about a father who initially refused to have his own last name put on his son's quilt panel when it was made shortly after his son's death. But later this father came to Kay after the opening ceremonies of the first local Las Vegas display that included his son's panel and he said, "It was time to put his son's name complete on the panel." Kay suggests that this emotional circumstance came about because "he grew and he was finally able to express really the love he had for his child and he was no longer trying to hide who his son really was." This story illustrates Burke's dramatist theories of guilt, purification of guilt and redemption. This father was obviously ashamed that his son had died of the so called "homosexual disease" AIDS and he was to guilty to admit this. But he was able to overcome his feelings through redemption helped by the power of the Quilt and its message of humanity, compassion and love for those who had died of this disease.
A similar story of transformation is told by AIDS Quilt researcher Krouse who related this story from an AIDS volunteer:

We were in St Louis, and there was a panel for a young man. And the (young man’s) father had gotten wind of it, called at the community house, and said, ‘I’m gonna come down with a shotgun and I’m gonna blow it away,’ and said you know, ‘Take down that panel.’ (The local host committee) took it down. But the father and the mother showed up. We didn’t know that they were there, but they had walked through the display. (The father) came up to the host committee and said, “I’m really sorry. I didn’t know what this was all about. My wife and I spend an hour here going through the panels, and now we’re gonna go home and make a panel for our son.

(Krouse, Gift Giving, Identity, and Transformation 253)

Explaining the transformational quality of the AIDS Quilt in her article “The AIDS Memorial Quilt as Cultural Resistance for Gay Communities,” Krouse says:

In sum, the quilt and its rituals draw individuals out of their isolated experiences of AIDS and its context in which gay identity can be emotionally, positively and collectively proclaimed. All these effects of the quilt – and the collectivizing effects that accompany the reversal of images of the dominant culture and the centrality of emotion and ritual to this process – are consistent with Taylor and Whittier’s (1992, 1993) recent suggestions about the working of social movement culture. (Krouse, AIDS Memorial Quilt as Cultural Resistance 75)

Exploring another aspect of my thesis about whether the Names Project AIDS Quilt was instrumental in motivating average people who are family and friends of people with AIDS to become AIDS activists, I asked Kay this question, “Would it be fair to say that the Names Project was your introduction and did it motivate you to become involved in the AIDS service business?” Kay’s response was:

Without a doubt. Yea ... Without a doubt. Actually it changed my life so much. The Names Project became very important to me... the positives that came from the terrible tragedy of losing Brent was a feeling of connection and togetherness and love and friendships that I acquired with
and through the Names Project and really from that point on I could not imagine doing anything without it having some connection to HIV and AIDS. (Valerdo. Personal Interview. May 24. 2001)

So again, I note evidence provided by a Burkean dramatistic reading of Kay’s response suggests that “Identification” created “connection and togetherness” and these were instrumental to her AIDS activism. And further, that this “Identification”, that was elicited out of devotion to the memory of her brother Brent, created a dedication and allegiance to the Names Project AIDS Quilt project and its mission to end the AIDS epidemic.

Ending AIDS? What a wonderful idea. But before that could happen there would need to be other benchmarks of social as well as medical progress to be made before we get there. With that idea in mind, I asked Kay about my theory that AIDS Quilt volunteers and panel makers became unwitting social activists through their association with the Quilt. The answer she gave to my question supports movement theory as articulated by social movement theorists John Wilson and Herbert Simons. My question to Kay was: “A thesis included in my paper is that in a covert way the Names Project turned a whole lot of people and families into unwitting AIDS activists – is that true?” Valerdo said, “Yes I agree completely.” Further answering she said:

Now Brent believed human rights should supercede my pet issue of women’s rights...and I think that’s how it all came to be the main issue – my father and I were delegates to the state Democratic convention in 1990 anyway, I don’t remember the year actually but anyway my father seconded the motion to add language to the party platform that articulated the Democrats desire to get rid of the sodomy law in the state of Nevada. And that was in tribute – you know certainly I was there, he was there and in the name of his son and my brother’s and I don’t think that would have happened had it not been for the Quilt and for what it made people aware of because it has, such a non-threatening
sensitive way it expresses the humanity – truly the humanity of people that we are all people. So yes I
think it definitely did that. (Valerdo. Personal Interview. May 24, 2001)

So socially and legally the gay and lesbian community in Nevada was the beneficiary
of the AIDS movement/Names Project AIDS Quilt activists that mobilized to positively
affect the legal rights of gays and lesbians in our state. The repeal of the Nevada “crimes
against nature” sodomy laws in 1993 was the result of the efforts of the Democratic
Party/AIDS activists who sometimes came together as Names Project AIDS Quilt
volunteers. So I argue this example of activism exhibits how the Names Project AIDS
Quilt qualifies as “social movement” according to John Wilson’s theory that, “social
movement is a conscious, collective, organized attempt to bring about or resist large scale
change in the social order by noninstitutionalized means.” (Stewart, Smith and Denton 2)

Further, I suggest the Names Quilt qualifies for movement status because it meets
Herbert Simon’s definition of social movements as “struggles on behalf of a cause by
groups whose core organizations, modes of action, and/or guiding ideas are not fully
legitimated by the larger society” (Stewart, Smith and Denton 2). So I argue that the
repeal of the sodomy statues in Nevada is evidence that the Names Project AIDS Quilt
should qualify as a social movement rhetorical artifact because its volunteers were
instrumental in changing how the dominant “larger society” imposed its beliefs regarding
the benefits of maintaining the gay and lesbian community as a “sexual outlaw” class of
citizens.

Gert McMullin – Names Project Production Co-ordinator

Another interview I did was with Gert McMullin who has been the production
coordinator of the Quilt since its inception in 1987. This interview with Ms. McMullin
took place on April 7, 2001, at a coffee shop in San Francisco, California, on the weekend that she was preparing to relocate to Atlanta, Georgia, to accompany the AIDS Quilt as it was moved to its new national headquarters. The primary focus of my interview with Gert concentrated on her 14 years of experience working with people who associated with the quilt, whether as panel makers or fellow AIDS activists.

Gert began answering my questions by telling me that the “AIDS Quilt saved her life.” When I asked her to explain this she said “All my friends were dying. I was really really unhappy and miserable. Nobody should hurt the way I hurt back then.” (McMullin. Personal Interview. April 7, 2001) Further explaining the atmosphere in San Francisco at the time she said, “Some of my friends were the very first people that were dying in San Francisco and it seemed like we were in a war zone with bombs going off all around and I was like – flipping out and I needed to be able to do something for those people.” When I asked her to explain how being involved with the Quilt helped she said, “The Quilt has given me one good thing and that is the ability to help others by being a surrogate friend and helping them to get on with their lives and that is the only good that has come out of all this” (McMullin. Personal Interview. April 7, 2001).

This indicates to me that the need for “identification” with her many departed friends was Gert’s primary reason for getting involved with the AIDS Quilt Names Project. “What drew me to it was that all my friends were dying...I needed a place where I could go where people could understand what I was going through and that’s what I found at the Names Project” (McMullin. Personal Interview. April 7, 2001). This need to be with others who can relate is powerful. Rybacki and Rybacki explain the Burkean concept of “identification is necessary to overcome substance so that the acting together that is
necessary for societies and their attendant hierarchies to survive can occur” (Rybacki and Rybacki 74). Rybacki and Rybacki then get to the heart of Gert’s reason for adopting the Names Project AIDS Quilt by explaining, “Unity is created through rhetorical activity in which common sensations concepts, images, ideas, and attitudes are symbolically expressed” (Rybacki and Rybacki 74).

A secondary focus concerned the rhetorical aspects of the individual quilt panels. Because of Gert’s access to the AIDS Quilt and the artifacts (letters) associated with it, she has had the ability through the years to witness first hand the storytelling capabilities associated with the AIDS Quilt. From this interview I gained insight into how panel making as memorial tribute helps to heal the psyche from the trauma and grief associated with the loss of loved ones and family to see if this could then be channeled into productive outrage and demand for social change.

Noting in Understanding AIDS: A Guide for Mental Health Professionals, regarding coping with the trauma of AIDS losses, Rich Bidgood (117) explains, “the AIDS pandemic has resulted in irreversible losses, which in turn, have led to pervasive and chronic grief for persons affected by and living with HIV/AIDS.” Treatment strategies of professional bereavement counselors suggest several ways to alleviate the effects of chronic trauma and loss due to AIDS including 1) repeated storytelling about persons who have died, 2) rituals to acknowledge aspects of loss, such as writing letters, 3) expressing trauma and loss non-verbally through art or music, 4) participation in community events such as candlelight marches and memorials, 5) making a quilt panel for the Names Project, 6) participation in community activities such as demonstrations and political action (Kalichman 118).
This short list of clinically recommended strategies suggests that Gert's choice of community involvements through the Names Project/AIDS Quilt was a sound and healthy choice. And further, I suggest that Gert's experience is indicative of others experiences and this supports my assertion of the healing value of participation with the Names Project AIDS Quilt.

Matt Kaminski – Names Project Office Receptionist

The last interview I conducted was with Matt Kaminski, a Names Project staffer who was the receptionist at the Names Project organization in San Francisco from 1999 to 2001 when he left the organization upon its move to Atlanta. The interview was conducted on April 7, 2001, at a coffee shop in San Francisco, California, and it was taped for my later use. Matt’s experience of the quilt is important because of his knowledge of how families and loved ones, upon visiting the Names Project office, became emotionally and psychologically empowered by their experience with the Quilt. Matt’s interest in the Names Project AIDS Quilt grew out of a general interest in doing AIDS service work.

During our interview, he did not indicate a personal need to do this work because of personal losses but because of his desire to connect to the families of the people who had died of AIDS. Again we see Burke’s theory of “Identification” at work but this time the connection takes place from the inside out. Matt’s assistance from the Names Project to the families provided them a way to identify with others who experienced similar losses and feelings and this was a community resource much needed all across America.
Matt’s connection to these families was very personal and heartfelt and he took great pride in his ability to help in any way he could. His sensitivity to the needs of these distressed families came through clearly during our interview. Noting his experience that the Names Project AIDS Quilt was the only place that some families had to turn to during their difficult time of need, Matt said, “Sometimes I could tell that people had no where to turn in their home towns for people to talk to. It was evident from our conversation that they needed to talk about their loss to be able to process their feelings and emotions” (Kaminski. Personal Interview. April 7, 2001). Further explaining the role the Names Project filled in many lives, Matt said, “I’ll get people calling from Nebraska or anywhere where they don’t have any support system and when they realize they have reached a live person that is understanding and compassionate they just start opening up” (Kaminski. Personal Interview. April 7, 2001). Finally to make the point of the invaluable service provided to families by the Names Project Matt said, “I would say that maybe I would get one or two callers a week that would just start crying and really open up and I would spend at least 10 or 15 minutes on the phone with them processing the death of their loved one” (Kaminski. Personal Interview. April 7, 2001).

The personal connection to grieving loved ones or family members visibly moved Matt to do his work at the Names Project AIDS Quilt and his willingness to personally assist the grieving process of the Quilt visitors was admirable and heartfelt and reflects my general impression of the desire of AIDS Quilt volunteers and staff to help lessen the pain and suffering of those left in the wake of the AIDS pandemic.
Dan Hinkley – Person With AIDS

My Quilt as Identification

St Petersburg, Florida 1987

So my experience as a gay man who feels empowered by my involvement in quilt activities goes back to 1987 when I attended my first candlelight memorial to commemorate the losses that were accumulating from the AIDS epidemic. I know I felt better after the ceremony that was held in conjunction with the very first quilt displays that were being created. The candlelight ceremony I was attending was held on an outcropping at a city park situated on Tampa Bay in St. Petersburg, Florida. Sadness was in the air, yet I felt empowered but did not know why at the time. I felt a part of a "collective" of people mourning the loss of recently departed friends. The sun was setting and the scattered clouds reflected a bright orange glow creating a colorful fiery environment that felt solemn yet invigorating. The end of the day was near, nighttime was about to fall. As a group who had come to mourn their lost friends we knew that tomorrow, with all its uncertainty would arrive. When Krouse discussed “gay identity” she makes a claim that the “effects of the quilt...reverse the images of the dominant cultures” with regard to social construction of what it means to be gay. My memory of that evening on the bay suggests truth to her claim because being a part of that “collective” that evening empowered me at the time to make a quilt for my friend Paul as well as to become more active in community AIDS activities.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
Las Vegas, Nevada 1992

The decision to make a quilt to honor my friends came about in the summer of 1992 during the height of the political campaign for President. My personal preference that year was for the challenger Bill Clinton who was then the governor of Arkansas. The President, George H.W. Bush, was running for re-election, but in my estimation he was a disappointment for many reasons but his lack of a forceful response to the AIDS epidemic was foremost in my mind.

My support for the governor’s campaign cannot be separated totally in my mind from my desire to make a quilt. The purpose, as I recall, was two fold, to make a statement in a way that the government would pay attention to and to begin to heal the personal pain I was experiencing because of the many losses I was experiencing. This healing began in October 1992 only days before the 1992 election when the Names Quilt with its 20,064 panel exhibit was placed at the backdoor of America’s White House, steps from the Washington Memorial in Washington, D.C. To get ready for this exhibit, many other Las Vegas AIDS activists and I, were busy organizing and preparing for that Washington, D.C., display by creating multiple AIDS quilts that would be given to the Names Project at the time of the display.

Emotionally, this was a difficult time for me because of several issues, but the most troubling was my recent sero-conversion to being HIV positive. I had recently relocated to Las Vegas to be near my family. The support they offered was welcome and seriously needed at that time. Two choices loomed as I began to deal with the new reality being an HIV positive gay man. My family was very supportive, which lessened many of my initial concerns about being ostracized and rejected as had been the experience of some of
my HIV positive friends. My first choice, like a couple of my friends, was that I could have just ignored the diagnosis and put it out of my mind as some people attempt to do. But because of the support I was receiving from my family, that didn’t seem like a reasonable idea, though in the back of my mind there was always the wish to escape my new reality. So my choice was not to turn away from AIDS but to embrace it in a way that would empower me over it. This decision seemed natural to me though I do note that many of my fellow HIV positive friends who made different decisions at that time are sadly no longer here. So I joined with the Names Project to do what I could to fight back in any way I could. As I was embarking down this new road, I took measures to improve the foundation of my health by making some long needed lifestyle changes to improve my health and I surrounded myself with like minded people who likewise chose to “not go quietly into the night.”

I did not consider myself to be a craftsperson, artist or sewing expert so in my mind I was limited to the potential of my making multiple individual quilts to honor my many friends. So I checked with the Names Project organizer regarding the panel making rules for quilts to be included in their large display. Kay Valerdo, the local chairperson, confirmed that the quilts need not be for individual AIDS victims but could be made to represent multiple names. The only basic rule was that the fabric quilt must be 3 ft x 6 ft, the same size as a common grave.

So I decided to make a quilt to honor all eight of my friends who had died from the disease since the beginning of the epidemic. Today, as I sort out my motivations, I can rank them according to their perceived importance at the time. Though political activism was a key, what I remember is that my primary motivation at the time was to mourn the
loss of my friends in a way that honored their memory as friends who made a significant contribution to my life. Additionally, I remember that I was searching to be a part of a group of people that was fighting back against the AIDS disease. So I created this panel as a means to personally identify with a group of AIDS activists that was fighting back.

As I began to plan the quilt I would make for my friends, I remember having much difficulty in organizing my thoughts and feelings about what to say or construct out of cloth, thread and fabric markers. Emotionally, I was caught in a very difficult place. I even remember questioning whether my departed friends would want an AIDS quilt created with their name on it. One friend who had recently passed away could not or would not even say the words AIDS or HIV though the disease was running rampant in our hometown of Dallas in the 1980's causing multiple deaths in our circle of friends. The only words Richard could muster to refer to AIDS or HIV was to call it “the bug.” It was an “out of sight out of mind” mentality and it was rampant in the gay community. Fear had taken hold and it was heartbreaking to endure because the fear of the unknown was causing behaviors that were undermining the collective strength and will of the gay community.

Many panel makers include materials of denim, silk, leather, cheesecloth, burlap, velvet and sometimes articles of clothing. Appearing on some quilts are t-shirts conveying musical tastes and political commitments, athletic jerseys, worn jeans and overalls, professional uniforms, chiffon dresses, and feather boas and hats of all kinds.

Having none of these things available to me to make my quilt I wondered at the time how to represent my friends best to Quilt viewers who would find their way to my quilt. My intention was to convey the importance with which I remembered my lost friends.
Because I did not have personal materials that belonged to each of them to build into the quilt panel, as many people do, to attempt to recreate the person being memorialized I decided to attempt to convey, not the person, but what the personal relationship meant to me.

The fabric color I chose for the background was black, the traditional color of “mourning.” First and foremost in my mind was the idea that I was missing my friends who had died from the AIDS disease. The eight friends lost were from the many “home towns” I had accumulated in my travels. As I look back, I remember the word “treasure” came to me first as I was considering the message the quilt was to communicate. The next selection I made was the “gold glitter” fabric paint that I used to write the simple message which said “October 11, 1992 To my friends, Michael Steiniger, James L Adams III, Douglas Hand, Paul Long, Boyd Stratton, John Loomis, Richard Saybolt, James “Cowboy” Easson.” The text that followed the names read “Memories of you are golden treasures cherished in my heart forever. Love Daniel.” Completing the panel was a golden satin cloth “box” complete with golden bow which represented the “cherished” gift of friendship which was now missing from my life. So as we were ten years into the AIDS epidemic, I made a giant stride to reconcile myself to an uncertain future. My panel was completed and boxed for the trip to Washington, D.C., and I was excited to make a trip to the center of power and influence in America.

Candlelight vigils honoring the dead are another memorial ritual that were commonly witnessed at Names Project Events in the past. This manner of honoring the dead has significant visual appeal and was used in Washington, D.C., to great effect. A personal memory I have of attending a march around the White House was inspirational and awe
inspiring in its scope. Thousands of people who had attended the 1992 Names Project Display were assembled in the ellipse behind the White House. At a preset time that evening we were all asked to light our candles and begin to move down the street behind the White House and up the street directly to the west of our nation’s President’s home. We then moved to the south side of White House and turned the corner and there in front of us were candles as far as your eye could see. Marchers were making a statement that evening that they would not forget the loved ones they have lost during this long national ordeal of the AIDS crisis. As that evening comes back to my memory today one point remains clear, I keenly remember that whenever I was in view of the White House I could not take my eyes off the windows of the home whenever it was within view. A memory seared into my brain is that in all the many windows of the White House there was not one single solitary candle burning which would have sent a signal to the marchers that we, the President and the First Lady of all Americans, understand your pain and your suffering and we are symbolically with you tonight. This memory is indicative of the problem, which the Names Project AIDS Memorial Quilt attempted to overcome. There was a chasm, or lack of “Identification”, between the nation’s leaders and the families and loved ones of those who were dying of AIDS and this chasm needed desperately to be bridged. The marchers did not believe our leaders identified with us, so we were reminding them of the importance of “Identification” with those who had died of AIDS. We were conducting a candlelight memorial to encircle the White House to make the point that all people with AIDS are important and that no one who dies of it should be forgotten or their memory tarnished because they happened to acquire what is simply a life threatening viral disease.
Final Thoughts

So for over twenty years now, there has been a momentous struggle for the hearts and minds of a society that has been affected by AIDS. Much of this struggle has been about how to make people better understand that AIDS is caused by a virus that can infect anyone and that AIDS is not a disease that only affects the gay community. This misconception has had a profound affect on the entire population of our country and sadly for a period of time it affected service delivery to people who were too sick to take care of themselves. The Names Project AIDS Quilt assisted tremendously with transforming this old perception into a new truthful reality. Cleve Jones and the founders of the Names Project set out simply to “claim the humanity” of those who had died from AIDS. While going about this great task with courage and intelligence they changed the course of American and world human events through the rhetorical acts of an AIDS Memorial Quilt.
CHAPTER 5

CONCLUSION

The most important thing I learned doing this study was that social movement activists can have a great impact on matters of immense importance to the social wellbeing of Americans. At the outset of the AIDS epidemic in the early 1980’s, the Centers for Disease Control, the Federal Drug Administration, and National Institutes of Health seemed ill-equipped to handle the new viral threat that AIDS posed to America’s health. There were several reasons for this dilemma but the two that were more troubling were the lack of funding and a lack of will. The shortfall in funding to fight the new public health emergency caused by HIV and AIDS was because America had slashed the budgets of its public health agencies greatly during the early 1980’s, and this limited the immediate response that could be generated against HIV and AIDS. Adding to this funding shortfall was an even greater threat of indifference or outright hostility to focusing public health priorities against the new viral threat caused by AIDS.

One of the more interesting and disturbing things I learned doing this study was that the primary reason for this indifference at best or hostility at worst, was simply homophobia, an irrational and unfounded fear of homosexuals. The reason why this homophobic fear became paramount in the minds of some was because unfortunately in America some of the first people to become infected with the blood born HIV virus were gay men. Gay men were not the only people infected at the outset in the early 1980’s but
because of the blatant homophobia exhibited by many in the Reagan administration, the
fact that this population was primarily becoming infected first became a fundamental
issue that was then distorted by the political enemies of the gay community. Then with
the help of the American right wing conservative Christians who found it politically
suitable to their cause, they began a debate about the morality of homosexuality and
chose not to focus on the issue of finding a cure for the HIV virus that was causing so
much death and destruction. Countering this institutional homophobia was the greatest
challenge the AIDS Quilt, as the rhetorical centerpiece of the AIDS movement, faced as
it battled the ignorance and fear that surrounds AIDS.

As AIDS was beginning to take its toll on America’s gay community, the destruction
was not simply the loss of life but was manifested as despair about the cultural
construction being created that cast members of the gay community as outcasts. This
wounding of the soul of the gay rights movement was caused when it was asserted by
many anti-gay political right-wing activists that AIDS was God’s answer to the “gay
plague”, which they used as evidence to question the morality of gay and lesbian
Americans. The AIDS Quilt at its outset was seen as a form of expression that arose
from, and had its most immediate appeal within, white middle-class gay male
communities. The AIDS Quilt was one type of response to discourses developing around
the AIDS epidemic, discourses that marginalized, stigmatized and condemned gay people
in newly devastating ways.

This debate about homosexuality and AIDS was a disinformation campaign intended
to distract people away from fighting the virus. Gay people and sexuality became the
primary issue that the mainstream media chose to focus on and not the virus that was
causing so much harm to American’s public health. A different kind of educational response was required that could help the public better understand the real impact that the AIDS disease was having on the American people and subsequently on American public health policies.

Cleve Jones, a San Francisco gay rights activist, understood better than anyone that the key to getting people to fight against AIDS was for people to better understand the significance of the human losses that were mounting because of the deadly AIDS disease. The AIDS Quilt was conceived in his mind as a potential rhetorical AIDS movement tool to help people better understand the human cost that AIDS was extracting from our society. During a protest in 1985 to mark the anniversary of Harvey Milk’s murder by anti-gay zealot Dan White, Jones asked the protesters to make small cardboard panels with names of people who have died of AIDS. When these small cardboards became plastered about after a windstorm, Jones saw in this scene at the Federal Building in San Francisco a vision of an AIDS quilt laid out in Washington, D.C., an AIDS quilt as a rhetorical artifact that would help bring into focus for the American people the tragic human cost that the AIDS disease was extracting from America.

The Names Project AIDS Quilt was officially organized in 1987 after much work by Jones and his fellow AIDS movement organizers in San Francisco. The activist work went on as panel makers and volunteers worked together with Jones to lay the panel out on the Washington, D.C. mall year after year during the late 1980s and into the 1990s. As a result, movement participants helped whittle away at the ineffectiveness of the established system forcing better health care to those sick with AIDS through fundraising
for AIDS service organizations, and by using the AIDS Quilt as an education tool, efforts at HIV prevention were begun.

This study of the Names Project AIDS Quilt as a movement study based upon its rhetorical power proved very educational and informative. To complete this thesis, I utilized three sets of theories, movement, rhetorical, and dramatistic to study the AIDS Quilt’s capacity to transform the public’s impression of the disease as well as its ability to mobilize and motivate AIDS volunteers.

To study movement theories I looked to the works of scholars Griffin, Cathcart, and Burke. The most important point that Griffin makes is that the rhetorical component of a movement is dynamic, has a beginning or inception, a development period, and a termination point when the movement has been fully consumed. Cathcart moved beyond Griffin’s work, claiming its too confining with its historical and socio-psychological limitations. Cathcart moved then to Burke claiming that a Burkean Dramatistic analysis best suits the study of rhetorical components of social movements. Burke’s dramatistic theory as it applies to movements suggests that drama is created out of “dialectical tension growing out of moral conflict” and that this “conflict” enables change and is a medium by which it can be studied and better understood.

Other movement scholars that I looked to include Stewart, Smith and Denton who provided a theoretical framework of five lifecycle stages that movements must go through to be considered authentic social movements. Using these stages as my outline, I inquired of Cleve Jones, the Names Project AIDS Quilt founder, as to whether and when the Quilt moved through the stages and what I learned is that according to Jones, the AIDS Quilt qualifies as a social movement tool. Jones confirmed his belief of when the
stages happened plus he added his opinion that another stage called mutation should be added, based upon his experience of the AIDS Quilt as social movement. What I learned from Jones is that the AIDS Quilt is currently undergoing a major change in mission to include not just the eradication of AIDS in America but ending the worldwide AIDS pandemic.

The first rhetorical theorist I looked to, to support my thesis that the AIDS Quilt is the rhetorical centerpiece of the AIDS movement was James R. Andrews. In an article he argued that any collective of people whose mission is to change society, must "alter, shape, and extend the ways in which the world is seen by those living in it." I believe that with his argument, Andrews articulates the core mission of the Names Project AIDS Quilt activists, whose mission was to "alter, shape, and extend" the ways in which the general public and the people afflicted and affected by it viewed AIDS. Cleve Jones explains this quite simply when he says the foundational inspiration behind the AIDS Quilt was to "claim the humanity" of those afflicted and affected by AIDS.

AIDS Quilt researcher Judy Elsley argues that the phenomenal success of the AIDS Quilt to mobilize volunteers and panel viewers at its frequent public displays is because of the rhetorical ability of the quilt to cure the national ills of "fear and prejudice" that surround AIDS. Elsley explains that the stories told in the AIDS quilt panels speak of the common values of partnership, celebration, love, family and loss and that by telling these stories the "Names Project quilt sets about claiming power for people with AIDS." Explaining how telling stories cures "fear and prejudice" Elsely says that it allows a rhetorical assault on the notions that separate people with AIDS from those not infected. The examples used by Elsely are based upon Susan Sontag's argument in AIDS and Its
Metaphors that AIDS has been “possessed” by political and military metaphors that have set up an opposition between “we” who are healthy and “they” who are sick dichotomy. Elsley’s argues finally that the Names Project AIDS Quilt allows people with AIDS to “repossess the rhetoric and thus reinscribe their stories” which will allow them to “claim dignity and status for themselves rather than be marginalized into mere victims.”

The major concept of Kenneth Burke’s philosophy of communication is to understand that humans are symbol using creatures who use symbolism to communicate with each other. Further, he argues that rhetoric is symbolic action and that humans are distinctly capable of using symbolism to act. To Burke “all the world’s a stage” and as humans we are all actors performing roles in life as actors perform roles on stage. The rhetor, whether making a speech, writing a book or taking part in a AIDS demonstration using an AIDS Quilt as a rhetorical centerpiece, is always taking part in a social drama while living and responding to society.

Dramatism is a Burkean theory explaining communication and how we use language as the primary mechanism to create purposeful change to our human condition. Several components of a dramatistic understanding of communication are: Hierarchy, Acceptance and Rejection, Guilt, Purification and Redemption, and Identification. While doing this study using these theories as analytical tools, I learned that the Names Project AIDS Quilt is a rhetorical artifact capable of creating purposeful change for the condition of those affected and afflicted by AIDS. The Names Project AIDS Quilt organizers frequently challenged the government and public health hierarchies in America to respond more vigorously to the AIDS epidemic. Acceptance and Rejection of people with AIDS caused much drama in America and according to Burkean communication theory what
naturally followed was change affected by rhetors who were involved in the drama.

Guilt, Purification and Redemption are psychological concepts that Burke uses to explain why people do what they do. People feel guilty about many things they feel or do, they then psychologically feel the need to purify their guilt to redeem themselves so they can feel better about their actions.

The last concept of Burke's that I found most instructive in doing my study was that of Identification. Rybacki and Rybacki (74) explained the rhetorical importance of this concept when they said, "Rhetoric must be viewed as identification rather than persuasion because its function is to proclaim unity." This is an important key to my study because the unity Identification creates, symbolizes common interests and cooperation between different persons or groups. This is important to my study because the "unity" or Identification discovered through the AIDS Quilt by panel makers and viewers alike, indicates that the AIDS Quilt is indeed effective operating as the rhetorical centerpiece of the AIDS movement. The result of its use as the rhetorical centerpiece has been to insure that those lost and memorialized in the AIDS Quilt would not be forgotten outcasts but would be honored as Americans whose only offense was acquiring an incurable illness.

A fundamental key to the transformation of forgotten outcasts to honored Americans was accomplished by the AIDS Quilt through its volunteers and activists because of its unique ability to reframe the "collective identity" of people with AIDS. According to L.A. Kauffman (Kauffman, 1990) collective identity is the shared definition of a group that derives from members, common interests, experiences, and solidarity. Substantively it has been my aim in this study to demonstrate that the AIDS Quilt was instrumental in
reframing the “collective identity” of the GLBT and GLBT supportive community as well as the AIDS infected and affected community. Additionally it has been my intention to show the AIDS Quilt encouraged the general population as well to engage in a wide range of social and political actions that challenged the dominant system to take action to fight against the AIDS epidemic. This was the case with all my interviewed subjects, including myself, and I believe we have all collectively demonstrated personal interest and involvement that helped make a difference and this would not have happened without the AIDS Quilt in use as the rhetorical centerpiece of the AIDS movement.

Much discussion about the AIDS Quilt identifies it as a socio-political phenomenon. It has been characterized as an artistic reflection of the epidemic disease and as a manifestation of cultural activism in the face of what often appears to be official unwillingness to acknowledge the devastating effects of AIDS on families across the nation. But the Quilt by virtue of its enormity (when fully displayed the Quilt covers twenty four acres and weighs over fifty tons) has become a narrative that also deserves recognition as one of the great epics of our time. Kimberly Rae Connor says, “It is one of history’s most powerful works of political art and creative, indeed spiritual vision.” (50)

In narrative terms the AIDS Quilt gains its enormous emotional power by creating sacred space where individual stories can be told and heard.

What I learned about social movements is that at their core they are about changing minds about issues or matters that can sometimes seem rather opaque to people. Movements aren’t always as visibly evident as an anti-war movement challenging a government’s war policy or the women’s suffrage movement challenging laws that affect our citizen’s basic constitutional rights. Movements don’t always march people through
the streets chanting inflamed rhetoric, blocking traffic, burning flags and effigies of disgraced fallen leaders. Sometimes movements are more subtle and change minds through matters of the heart. This was the case with the AIDS Quilt as it played its part as the rhetorical centerpiece of the AIDS movement.

The AIDS Quilt changed hearts and then minds about the importance of people fighting back to conquer a disease so that it could not run rampant, needlessly killing countless innocent people. The AIDS Quilt taught people many things. People learned AIDS was not just a homosexual disease yet it was true that many of the very first losses were primarily gay men. People learned that gay people have loving caring relationships with lovers and family, just like heterosexuals. People learned that AIDS affects everyone because AIDS does not discriminate against whom it strikes. People learned that AIDS is simply a disease caused by the HIV virus and everyone is susceptible to its life threatening infection. When these hearts and minds were changed through interaction with the AIDS Quilt, AIDS prevention became more important in the minds of the American people and their government leaders. And caring for people with AIDS became a much better funded and evident priority for the public health system of America.

Further study I would suggest would be about the African AIDS quilt and how it could be more effective in the fight against AIDS in Africa. Cleve Jones is hopeful that the Quilt can have a positive impact on AIDS discussions in future world AIDS forums. And additionally, this Names Project AIDS Memorial Quilt could serve as a model of minority initiative and activism for other populations that may face similar circumstances.
in the future but with the knowledge that “memorialization” done effectively can have a motivational impact on a population of people.

My final thought in this study concerns how the AIDS Memorial Quilt has been used in the past and its aspects for a future. Originally, it was conceived as an organizational tool. At its first display, it immediately became a mourning tool. Other more recent uses find that the AIDS Quilt is an educational tool, and now it has become an AIDS prevention tool. Why? Could the Names Project AIDS Memorial Quilt become the primary AIDS prevention tool in our culture’s arsenal of preventative measures? Or perhaps the world’s answer to the fight against AIDS? Time will tell but I believe in this study I have demonstrated that the AIDS Quilt can be understood as resistance to a construction about being gay and having AIDS that was, and continues to be, as threatening to gay men as the virus itself and I believe this is a monumental contribution to human understanding.
Appendix I

Interview Questions

University of Nevada, Las Vegas
Greenspun School of Communication
Research Study: Names Project AIDS Memorial Quilt
Researcher: Daniel Hinkley

My research study is going to be a qualitative study during which I will be studying the rhetorical qualities associated with the Names Project AIDS Memorial Quilt to ascertain the effect it has as a part of the AIDS social movement. Listed below are samples of questions I will be asking my research subjects during the interviews. These five adult subjects are past staff or volunteers for the Names Project AIDS Memorial Quilt.

1. How long have you been associated with the AIDS Quilt?
2. During this time what are your most significant memories associated with it?
3. During your association with the AIDS Quilt do you remember any circumstances associated with its exhibits that you remember that caused panel makers or Quilt viewers to become more active in the fight against AIDS.
4. Can you give me any examples of significant individual AIDS panel quilts that you remember the most and why are they significant in your mind.
5. As a mourning instrument for people who have lost loved ones to AIDS, why do you think the AIDS quilt is so powerful?
6. Have you made any AIDS Quilt panels and why did you do it. Do you remember how you felt before and after you made the quilts and turned them into the AIDS Quilt volunteers?
7. As you look back at the long 14 year history of the Names Project AIDS Memorial Quilt can you identify the similarities or differences between this project and others such as: ACT UP or GMHC.
8. There are five phases of social movements, which I will list: can you tell me when the Names Project moved through each of these phases and what do you remember about that movement, i.e.: significant problems or benefits at each phase.
9. During Names Project displays, names of people who have died from AIDS are read aloud. Why do you think this ritual associated with the Names Projects affects people as it does?
10. Another ritual associated with the Names Project displays are the candlelight vigils, do you have any personal memories of marching past the White House and Congress to make a personal political statement?

11. Is the Names Project a memorial or a movement or both and has it succeeded its original mission?

12. Narratives have played a large part in the panel maker’s desires to tell the story of loved ones lost. Can you identify the best narrative panels in the AIDS Quilt?

13. Many people have said the AIDS Quilt is a metaphor for Americana and it’s the reason for its success, do you agree?

14. Do you remember any conversation or can you provide evidence that the AIDS Quilt displays in Washington, D.C. had any impact on our government’s response to the AIDS crisis in America?

15. The primary strategy of the Names Project has been to create a consensus, a myth of inclusion. Could it have done a better job of creating this myth and how?

16. The Names Quilt is moving to Atlanta, why and what impact will this have on the organization and ultimately on its mission.


Ellis, Carolyn and Bochner, Arthur P. "Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject." Denzin, Norman K. & Lincoln, Yvonda S.


Griffin, Leland. *A Dramatistic Theory of the Rhetoric of Movements: In Critical Response to Kenneth Burke*, Ed. William H. Rueckert, Minneapolis, MN:

University of Minnesota Press, 1969.

Groff, David “Keeping Up With the Jones”, *POZ* (September, 2000), 65-67.


VITA

Graduate College
University of Nevada, Las Vegas

Daniel Hinkley

Home Address:
1808 South 17th Street
Las Vegas, Nevada 89104

Degrees:

Associate of Applied Science (AAS), 1973
Monroe Community College, Rochester, New York
Bachelor of Business Administration, 1975
University of Miami, Miami, Florida

Thesis Title: NAMES PROJECT AIDS MEMORIAL QUILT: A Rhetorical Study of the Transformation of an Epidemic Through Social Movement

Thesis Examination Committee:
Chairman, Dr. Richard Jensen, Ph.D.
Committee Member, Dr. Anthony Ferri, Ph.D.
Committee Member, Dr. Larry Mullin, Ph.D.
Graduate Faculty Representative, Dr. Esther Langston, Ph.D.