Aids Coalition to Unleash Power: Changing through movement, leadership, and Internet capabilities

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AIDS COALITION TO UNLEASH POWER: CHANGING
THROUGH MOVEMENT, LEADERSHIP,
AND INTERNET CAPABILITIES

by

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Bachelor of Arts in Psychology
University of Nevada, Las Vegas
1997

A thesis submitted in partial fulfillment
of the requirements for the

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ABSTRACT

AIDS Coalition to Unleash Power: Changing Through Movement, Leadership, and Internet Capabilities

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The examination of AIDS Coalition to Unleash Power (ACT UP) past and present shows a vivid and often extreme organization, branching from Gay Men's Health Crisis (GMHC). Both groups were formed by Larry Kramer, who has played a large role in the gay liberation movement in the United States. This study provides a map of the decline of ACT UP with regards to the decline in public fear of AIDS, the resulting decline in public interest, and the ineffective leadership strategies of Larry Kramer. In addition, this study offers a hypothesis for better exposure; a possible symbiotic effect between the Internet (passive) and humanistic (active) devices. In mapping ACT UP's use and misuse of leadership and communication, this study will provide a clear view of the path ACT UP has taken, in addition to posing a better way of promoting information to current audiences.
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CHAPTER I

AN OVERVIEW OF AIDS COALITION TO UNLEASH POWER

Overview

This qualitative study investigates the relationship between social movement trends, changes in leadership, Internet availability, and AIDS Coalition to Unleash Power (ACT UP). The examination of ACT UP past and present shows a vivid and often extreme organization, branching from Gay Men's Health Crisis (GMHC), started by Larry Kramer. The very nature of 1980s GMHC and ACT UP discourse was shock value; making people tune in whether or not they liked what was being said. This is apparent in the slogans used by ACT UP, "Silence = Death" and "Knowledge = Power" (Bayer and Kirp, 1992, p. 39). ACT UP presently is significantly more staid; the decline in shock techniques coming with the life cycle of the gay rights movement, the lack of empowerment of group leaders, and the introduction of the Internet.

This study provides a cognitive map of the decline of ACT UP with regards to the decline in AIDS morbidity, the decline in public fear of AIDS, the resulting decline in public interest, and the ineffective leadership strategies of Larry Kramer. In addition, this study offers a hypothesis for better exposure; a possible symbiotic effect with Internet (passive) and humanistic (active) devices to increase and maintain public interest.
while veering away from words as weapons, which may turn the public away from the issue rather than piquing interest. AIDS awareness is a serious issue that has been losing momentum with the gay and straight public. In mapping ACT UP's use and misuse of Internet capabilities this study will provide a better way of promoting information to retain current audiences and pique interest in new audiences.

Larry Kramer, the founder of ACT UP, will be discussed as a figurehead and massive force within the group - once upon a time. The changes in the group over the past 10 years have included the removal of Kramer and his views, along with a decrease in public interest and activity within the group. Barge (1989) suggests that feeling empowered means having “a heightened sense of self-efficacy – of powerfulness, self-determinism, and confidence in their ability to perform a task” (p. 247). Barge’s model of leaderless group discussion is useful in describing the difficulties Kramer set up in his reign as an ACT UP leader. Barge (1989) found that “an individual leader’s behavior does not necessarily aid groups in achieving their goals but that group leadership behavior does” (p. 245). Kramer’s inflammatory speeches made to the public are no longer a cornerstone of ACT UP’s front. Rather, combining the recent Internet shift with the lack of empowerment mixed with the natural life cycle of a movement provides a bleak future view for the organization.

The availability of the Internet, ready for use and readily attainable in the United States, has provided an open forum for opinion on a variety of topics. ACT UP began with the mindset that to reach the general public the group must be highly visible. The power of the Internet to creep into millions of American homes seemed like an inexpensive and quick fix for mass exposure, yet the effect instead may be a decrease in
knowledge, awareness, and understanding. In 1998, one in four U.S. households was on-line (Biagi, 1999, p.209), showing that the mass numbers of people who have access to the web pages are not all seeking them out. ACT UP has become decreasingly visible over the last ten years, and the Internet does not appear to be making positive changes in the visibility of the group. This study outlines the contributing factors for the continuing decline of ACT UP visibility and proposes changes that could prolong the effectiveness of the group’s message.

While the World Wide Web provides an inexpensive and easily accessible way to promote organizations and provide information, it has moved the group presentation from an active (humans acting out) front to a passive (computer-mediated communication) front. A front is defined as a compilation of three different types of communication: Manner, setting, and appearance (Adler, Rosenfeld, Towne, and Proctor, 1998, p. 126).

The framework for this research project is Bolter’s idea of Virtual Reality and the redefinition of Self (Strate, Jacobson, and Gibson, 1996, chapter 7). Bolter claims that “cyberspace is a graphic space, and the role of prose, of discursive written communication, in cyberspace is problematic” (p. 106).

In discussing the redefinition of Self on the Internet, AIDS stigma and social roles come into play. Beginning with the idea that Self was once community and interpersonally-based, I will map a history of AIDS, with marked changes occurring with decline in public interest, changing leadership, and the onset of a vastly available Internet. The change in Self then leads to changes in the dissemination of information.
Rather than a singular "Self", I propose a group "Self" within ACT UP as a once-extreme group with chapters in many cities.

In order to discuss changes in ACT UP as Internet access has changed the policy landscape and public opinion, questions have been formed to analyze ACT UP pages on the Internet. Those questions, based on Schultz and Barton's 1998 model include: Who is the leader/creator? Is there any sort of bias evident? How up to date are the links? Is the web page visually appealing (i.e. vibrant colors, interactivity, shock value)? Do the graphics and art serve a specific function or are they merely decorative? In addition, are there links provided to other similar groups (1998, p. 8)? Cyberspace and the World Wide Web have played major roles in the nature and availability of ACT UP today.

History of AIDS Information and the Public Interest

Darsey (1991) provides a solid historical-rhetorical overview of the AIDS pandemic. The study provides insight into relationships between AIDS rhetoric and history, emphasizing rhetorical change within the gay rights movement. He attempts to solidify a framework whereby the pandemic can be mapped. The author points out that the gay liberation movement in the United States is especially useful for theory-building studies. There is a specific point of origin in the pandemic, while the duration spans nearly twenty years. The organizations, publications, and spokespersons are accessible and easily researched, and there is an abundance of information about the gay rights movement and AIDS.

Darsey (1991) specifically studies catalytic events and five rhetorical periods from the gay liberation movement in the United States. The five significant rhetorical
periods include establishing groundwork, followed by a period of education and encouragement, moving towards strength and independence, veering into a period of aggressive self-identity, ending in uncertain maturity (pgs. 45-63). Catalytic events serve to punctuate the progress of movement discourse. The author explains that “a catalyst is a chemical that is used to speed up a reaction, a reaction that would have occurred anyway, only much more slowly” (Darsey, 1991, p. 61). In mapping the pandemic, Darsey provides prominent value appeals for each period: Unity, Work, Determinism, Strength, Achievement, Tolerance, Truth, Justice, Safety, and Security. While discussing the catalytic events, the value appeals in each event/period become apparent. These stages are imperative in mapping the pre-ACT UP AIDS pandemic. They provide a logical framework for the movement, leading to further study in leadership in AIDS-related groups.

Beyond the framework for the AIDS pandemic there is the issue of how the AIDS pandemic is racially and sexually composed. Wolitski, Bensley, Corby, Fishbein, and Galvotti (1996) researched sources of HIV information in five inner-city neighborhoods. They examined practices contributing to HIV risk: injection drug use, sexual contact with an injection drug user, prostitution, and/or sex with a male partner (for men). The sources of HIV/AIDS information varied per person. Where the information is attained is extremely important, as the media is discussed as both an enabler and a debilitator. Mass or small mass media sources (specifically television) and interpersonal conversation (friends and family) were the sources of information. This is particularly interesting with regards to computers as a new medium. The Internet has the possibility to be both mass and interpersonal. Exposure to specific mass and small media sources
was related to gender, ethnicity, and risk status. Women and individuals at risk of HIV infection were most likely to have talked with someone about HIV in the past three months. The authors also found that African Americans were less likely to have discussed HIV with friends and family. Differences associated with gender, ethnicity, and risk status were also observed by the authors for interpersonal information sources.

The AIDS pandemic was originally classified as a “Four-H Disease” (Grmek, 1990). Those four H’s include homosexuals, Haitians, heroin addicts, and hemophiliacs (p. 31). Some added a final group, hookers, raising it to a five H disease. Grmek (1990) details how the disease came to be named AIDS, Acquired Immune Deficiency Syndrome, “suggesting a clinical, not a pathologic, concept” (p. 33). Grmek (1990) gives insight as to how the AIDS pandemic began in the United States, and how the distribution of cases by risk group evolved. The percentage of male homosexuals, who represented 92% of all cases reported until 1982, decreased to 75% by January 1983, and about 72% toward the end of 1984. The majority of these patients were white, aged thirty to forty, and were well-educated. Their principle risk factor was pronounced to be sexual promiscuity (p. 41). This played a large role in the mental construction of AIDS within the United States. The roots, or beginnings, of AIDS as a social and physical ill are marked by pre-existing beliefs about homosexuals, mixed with the statistics showing gays to be the hardest hit group.

an important piece of the national dialogue of that time. The authors suggest that the report, along with the media attention that it received, shifted the socio-political environment concerning AIDS and pointed to President Reagan's silence concerning the issue as a lack of presidential leadership (1995). The case study suggests that to be effective, discourse has to offer more than a simple reiteration of presidential concern about the problem. The media focus on the issue served to magnify the lack of presidential leadership on the issue of HIV/AIDS awareness and treatment. The authors make the statement "If speaking is equated with leadership, an extended public silence about an important issue may not be politically feasible...an extended crisis will eventually force the president to address the issue publicly" (p. 29). Reagan is viewed as a temporary block of AIDS information, playing a large role in the spread of the disease. The media once again played a large role in disseminating the information available to them, passing it to the public in small, easily chewable chunks.

The United States has provided a tough audience for AIDS information dissemination. Bayer and Kirp (1992) discuss the strains on the U.S. system of governance; "in ideological terms, the story of AIDS is ultimately not a tale of conspiracy-building and witch-hunting of the kind urged by the vocal extremists, but more a tale of consensus-building across professions, political ideologies, and sexual preferences" (Bayer and Kirp, 1992, p. 7). AIDS changed policy landscapes, from rules about privacy to the structures of funding. The authors point to the anti-gay trends in American culture, an administration consistently minimizing the issue of HIV/AIDS and "denigrating those who urged a more activist national role." Bayer and Kirp (1992) discuss four major transformations occurring in the first decade of the AIDS epidemic:
The epidemiological shift in focus from gay white males to black and Hispanic drug users, the clinical advances in therapeutics, the changing public health policies, and the ideological focus of policy debates. They conclude that as the process of “normalizing AIDS” progresses, the policies for prevention and care will become increasingly open and accessible" (p. 44). Indeed, the past ten years have shown marked change in accessibility to care, but the policies for prevention are arguably weak. The issue of prevention has changed in this computer age, and the messages once sent through conventional means (television and face-to-face) are now left in a passive Cyberspace.

HIV/AIDS and Media Communication of Stigma

A major issue in the AIDS pandemic has been the way the people with the disease have been ostracized. Gilder (1989) has analyzed the processes by which gay people see themselves in relation to the social construction of AIDS discourse, both as individuals and as a collective (1989). The author describes the self-image of a marginalized population, victimized first by a disease and then by the general public. AIDS was seen as the fault of the victims, who were primarily gay men. Gilder (1989) concludes that AIDS has succeeded in limiting the advance of the gay liberation movement due to the evolving ideas about gay sex. He claims that “one way for the gay community to achieve collective power again lies in their rejection of the labels of ‘objects’ and ‘victims,’ and work for a self-interpretive construction of AIDS and its definition” (p. 36).

Previous research has suggested that attitudes towards various aspects of the AIDS issues are primarily motivated by symbolic attitudes concerning homosexuality and gay rights. Using data from the 1988 General Society Survey, Jelen and Wilcox
(1992) show that the attitudes towards AIDS policies are differentiated by various types of possible government actions, and that only some of these are significantly related to homophobic attitudes. While some AIDS policies are typically related to general attitudes toward government assistance to disadvantaged people and to public health spending, the effects of these values are often independent of the effects of symbolic attitudes toward homosexuality and gay rights. Specifically, anti-homosexual attitudes have been shown to indirectly inhibit informed attitudes about AIDS. Not surprisingly, people who are anti-gay (labeled as “symbolic” values and attitudes) are resistant to government spending for disease research and also are more likely to fear contact with people with AIDS, who are assumed to be primarily homosexual.

The media can play a large role in the transmission of AIDS information. Schwartz and Murray (1996) point to the media as not only a prospective misinformer of scientific “fact” but also show that science often speaks in an extremely qualified manner. The media may not convey the whole truth about AIDS. The authors discuss the epidemic in terms of stigma by way of homosexuality, drug abuse, and as a universally fatal disease. The media put a pessimistic spin on many scientific findings related to HIV/AIDS: “In several notable instances, major media outlets have de-emphasized or ignored comparatively reassuring news about the epidemic’s development” (p.61). The authors point to the tendency of the media to universalize by emphasizing the risk to an entire age group or sex – as opposed to emphasizing the particular behaviors characterizing some individuals in a larger group. For example, media sources may discuss young black men as a risk group without giving due notice to the importance their sexual practices play. The authors note that “because race and
ethnicity are not risk factors for HIV infection, an assessment of risk behaviors is necessary to properly target prevention efforts" (p.68).

While sexual behavior plays the largest role in the AIDS pandemic and also in public stigma, the gay-as-guilty premise gained momentum in a series of steps. Many people wanted to believe it was solely a gay disease, whether it be in relief at having someone to blame, a moral mindset regarding homosexuality, or the feeling that they, the straight public, were not at risk. The large response to AIDS by the gay community led to further blame for the disease. The first newspaper article on HIV/AIDS appeared on August 8, 1983 in The New York Times. The author, Robin Herman (1983), writes of “a serious disease whose victims are primarily homosexual men” (p.32). At the time, two new cases a day were being recorded at the disease control center, and the article “A Disease’s Spread Provokes Anxiety” was placed in section “L”, in the back of the paper. The media veered away from coverage of HIV/AIDS. Even after the original breaking of the story, the media either left it alone or sensationalized it. “Dr. David Sencer, New York City’s Health Commissioner...emphasized that groups other than homosexual men were involved” (p. 32). For one moment it seems as if the straight population should be concerned about the spreading disease. However, groups afflicted with the syndrome include more than “60 heterosexual men and women who were drug abusers and used intravenous needles; 30 male and female immigrants from Haiti, all heterosexual, and some hemophiliacs who used blood products to combat their illness” (p.32). The middle-class, heterosexual, white population had no reason to assume this epidemic would ever reach them. This was the beginning of the AIDS pandemic, a start to the prejudice and stereotyping of a disease.
There have been many discussions on the nature of AIDS, including the ways the public thinks about the disease and the meanings, which have been attached to it. Bird (1996) tells the story of a letter sent to Ebony magazine from a person signing her/himself “CJ, Dallas, Texas” (1996). The writer of the letter, CJ, claimed to be infected with the AIDS virus and having sex with four men a week in order to infect them. The letter led to a surge of calls to a radio talk show, which led to local and even national news coverage. It was later found that a 15-year-old girl who wanted to raise awareness about the disease wrote the letter.

The story is cited as a product of oral folk tradition that has become transformed into news. Like folklore, news is a cultural construction; a narrative that tells about things of importance or interest, and reinforces and reflects cultural anxieties and concerns. “Cultural researchers have sought to show that the line between news and legend is not really that clear” (Bird, 1996, p. 55). The media are shown to feed from rumor and folklore, and retell these stories as truth. Bird describes how the media are simply reflecting the concerns of the culture around them, “…because the story reached so deeply into cultural fears and stereotypes, it took on a life of its own” (p. 54). AIDS representation in folklore literature is present in the form of jokes, legends, and other folk responses. Newspapers, magazines, television, and word of mouth all serve as vehicles for information, fact and fiction. While the CJ incident was not intended as a hoax, it was the construction of a story made possible by oral tradition and public fears, mixed with pre-existing beliefs.

Another problem with media attention is the selling of news that middle America wants to hear, leaving out elements that are important to the whole picture. Rotello
(1996) writes of “The Twilight of AIDS”, whereby the AIDS epidemic “is finally yielding to the battering ram of science” (p.16). Or is it? The author discusses the revolution in the way AIDS is treated, including the excitement in the gay community as many men literally rise from their deathbeds and prepare to resume a semblance of normal life pre-AIDS.

Is the pandemic coming to a close as the media would so often have us believe? Rotello (1996) mentions that there is a large, though often unmentioned, downside to the happy findings. That is, the “cure” is not working for everyone.

The cocktail is toxic, difficult to absorb, and extremely expensive. No one knows how to best administer the drugs, or to whom. Resistance to the drugs may erupt in strains of the virus that can easily pass between people: “We’re walking an exceedingly fine line between eradicating the disease and making it much stronger” (Rotello, 1996, p. 18). Rotello (1996) warns of misguided optimism, especially through the media. The medications which eliminate the virus in some patients, giving the impression that AIDS is curable, may lead to widespread media coverage of that fallacy. False beliefs of a perfect cure could lead to an increase in infection rates through elevated sexual activity without regards to consequence. With regards to current technology, the beliefs that a cure is here have led to a marked relaxation within the public and a decrease in interest in AIDS-related organizations.

The media and public misinformation can lead to an even greater problem. Kinnick, Krugman, and Cameron (1996) describe the new phenomenon of compassion fatigue. Using a telephone survey methodology, the authors measured compassion fatigue, or desensitization and emotional burnout. This “numbing of public concern” was
applied to four social problems: AIDS, homelessness, violent crime, and child abuse (p. 702). The concept of "compassion fatigue" was first used to describe a decline in compassionate feelings toward patients of clients by people in helping professions. Now, it appears that the media are contributors to the desensitization to social issues by the general public. The overexposure to social problems has left the public numb. Particularly in situations where the public perception is that the victim is to blame for his/her problem, as is the case with AIDS, there is a high instance of compassion fatigue.

The authors point to the end result of a homophobic and fearful media. That end result is compassion fatigue, and "while news coverage of social problems may initially serve as a facilitating role in attracting attention and resources to problem amelioration, pervasive coverage which emphasizes problems without solutions may actually backfire and create a numbing of concern toward social problems and their victims" (Kinnick, Krugman, and Cameron, 1996, p. 703).

There is an apparent trend in AIDS coverage in the mass media. The beginning of the pandemic was marked by media apathy for a disease which the straight public did not believe would or could affect them. Once it was proven that the disease did not discriminate between age, class, sex, race, or sexual preference, the media became saturated with HIV/AIDS information, much of it half-truths. While the intent to provide information may have been sincere, the type of information being provided was based on blame for a homosexual and marginalized group. The straight media pushed the AIDS story to the point where the straight public has gotten compassion fatigue from an overexposure to information about AIDS. The loop has led to the continuation of
perceptions of AIDS as a gay disease, and the homophobic overtones in much media coverage enable the general (straight) public to ignore the victims and the disease.

Activism within HIV/AIDS Awareness Groups

Without activism, the gay rights movement would never have become an issue presented to the straight public. There are extensive studies of individuals and groups involved in activism, many centering around the gay rights movement and the effects of HIV/AIDS on public response.

Jennings and Anderson (1996) theorize that expectations about why groups and social movements differ in terms of their support for confrontational tactics can be applied to subgroups within a larger set of political activists. They found that support for ACT UP is encouraged by the strong beliefs, personal suffering, commitment to the ideological standpoint, and differing lifestyles of AIDS activists. The authors point to the strong effects exerted by sexual orientation, yet found that distrust and dissatisfaction had little impact on support for ACT UP: “The question of when people are more likely to support disruptive and potentially violent behavior in the pursuit of political goals has been an ongoing concern for students of collective action” (p. 330). The authors note that a group must be aware of how it is affected by an issue and that awareness itself is subject to social control. With the organization ACT UP, many members came to the group from other social movements, bringing with them previously learned organizational and analytical skills. A particularly interesting idea posed in the research is that of the history of science being composed of the histories of technologies, ways of
life, social order, and visual practices. In order to look at a disease, one must look at the
culture and history of the people affected by that disease.

Ariss (1993) explains social theory that places emotion in socio-cultural and
political contexts rather than from mental states. Rather than emerging from some inside
core of the human psyche, Ariss (1993) believes that anger can be constitutive of both
social identities and forms of social practice. The case examples are political events in
the late 1980s, which led to the formation of ACT UP. "The group formed in reaction to
a perceived routinisation of community-based AIDS service organizations which, it was
argued, had resulted in the loss of their transgressive political capabilities" (p. 18). The
author explores the phenomenon of the strategic expression of anger for a political
objective. He describes the process by which ACT UP branched out to Australia,
forming another chapter beyond the United States. Finally, he focuses on the importance
of emotion in relating the message through the media: "Their images of angry activists
have worked to re-construct the social identity of the HIV infected, shifting
representations away from the passive and immoral disease 'victim', towards an active
social subject" (p. 19). AIDS is so often labeled an emotional issue, as was discussed
with regards to stigma. The construction of AIDS went beyond the disease itself to
include very specific labels for the people afflicted with the illness. He describes the
effectiveness and uses of anger in an extremist AIDS organization, aiming for public
awareness.

The AIDS epidemic was a jolt for the gay community. It was immediately
labeled as a gay disease and the stigma attached in such a way that it is, to this day,
labeled as a gay disease (in the United States). The sluggish response of governmental
figures combined with the fear and anger of the public led to formation of AIDS support and informational groups, led by gay community leaders.

Allen, Mor, Fleishman, and Piette (1995) look closely at the organizational transformation of advocacy as they question growth and development of AIDS community-based organizations. Specifically, the phenomenon of “goal displacement” is important to groups such as Gay Men’s Health Crisis and AIDS Coalition to Unleash Power. It refers to the organizational drift, whereby the gap between the founders’ ideals and intentions and the organization’s evolution becomes wider. The authors mention the criticism from Larry Kramer, founder of GMHC and ACT UP to the evolution of GMHC into a formalized service agency, as “his position was that offering care takes resources and energies away from activism” (p. 54). While many organizations accept the change from merely outspoken witness and advocate into health care organization, Kramer opposed taking on dual responsibilities saying one would steal time and energy from the other.

Discussion of Thesis Goals

This thesis outlines the framework by which AIDS has developed into a media discussion, advertising stigma, hypothesizing that in addition to the normal life cycle of a social movement and public interest, the media growth and advancement present within the World Wide Web has stunted AIDS Coalition to Unleash Power (ACT UP). The changes in leadership will be studied with special attention placed on Larry Kramer. His expressive and extreme style of leadership may have raised awareness, but also turned off much of the public. Changes in ACT UP as part of a social movement will be
studied, with emphasis placed on the new influences of the world wide web. The web makes a large impact on society. The ramifications of changing a health organization based on extremist action, present in a socially sensitive area, from active involvement to passive information are immense. In fact, the Internet may promote laziness by group leaders who feel that providing the information is the same as action. While the world wide web provides opportunities that were previously unavailable, it also has lessened the real-world involvement that organizations, specifically ACT UP, have relied upon for public relations. The ACT UP webpages will be analyzed for effectiveness and availability.

This chapter has defined AIDS as a belief system rather than as a disease; a public issue risen to new levels by stigma, tying a disease into the theories that Darsey (1991) offers, as well as information on how the foundation for HIV/AIDS research influenced stigma within the United States and also how the gay rights movement has had to recoup and adapt to the changes that HIV/AIDS has made in their battle for equal rights. The history of HIV/AIDS and gay rights has been brought into play as a facilitator and instigator of stigma, as well as a catalyst for the formation of extreme action groups.

The literature on stigma will be discussed in chapter II with a discussion on media involvement, including changes the Internet has prompted. The existing research will be brought to light regarding media involvement and HIV/AIDS stigma. Chapter II will be an extension of chapter I, including media aspects to compliment the gay rights issues and a discussion on the influence that language and culture have had on AIDS stigma and the gay rights movement.
Chapter III will begin with a history of ACT UP, posing the following questions: What is ACT UP? Who are the leaders? Where are the active chapters of ACT UP? What are their goals, including perceived and presenting? What motivations do they have currently, as opposed to those they had ten years ago? This chapter will briefly detail ACT UP as a gay rights group, beginning with the formation of Gay Men's Health Crisis. Larry Kramer, the founder of GMHC and ACT UP, will be a focal point for discussion. His views have radically changed the treatment of HIV/AIDS via the groups he began in the early 1980s. History is doomed to repeat itself if one does not understand or strive to make changes to adapt to what was previously unsuccessful. Kramer made similar mistakes with both GMHC and ACT UP, resulting in an alienation from both groups.

Many factors play a role in the transformation of ACT UP from primarily active to primarily passive. First, the Internet is too easy a tool. While once the activists were on street corners, in churches, in the public eye, now they are on a Website. The site may be available to more people, but the information is of such a delicate nature that the general public rarely accesses it. One must have a pre-existing interest in HIV/AIDS, the gay rights movement, and ACT UP specifically to access the site. Second, the past ten years has been saturated with media attention directed at the HIV/AIDS battle. Indeed, it is no longer a battle in the media eye, but rather a ten-second sound bite on the news when another breakthrough in medical research is announced. New diseases have cropped up, new issues have come to the forefront, and HIV/AIDS is no longer perceived by the public as a complex monster. Rather it is a disease which many people live long, seemingly healthy lives with. Lastly, the groups affected by the disease have changed
since the inception. While the Gay Plague was feared and discussed to death, HIV/AIDS is now seen in large numbers of the elderly, as well as women, teenagers, and across every social spectrum. The unity of ACT UP came primarily through the similarity of activists. That unity has changed as membership and lifestyle and beliefs have changed.

Chapter IV will discuss the current Internet information. While the review of research includes a thorough presentation of the HIV/AIDS pandemic from start through present, there is much research left to be done. There are certain gaps in the information about ACT UP, especially since the introduction of the Internet. The last five years have shown a marked decline in ACT UP activism as media exposure has died down, died out, and the issues that were relevant in the mid 1980s are no longer pressing. I also propose that the introduction of the world wide web has made ACT UP leaders in every chapter feel as if they are reaching more people, when in fact they are slowing down the interest of the public in their groups. In this qualitative study, I will be using Schultz and Barton's (1998) line of questioning to analyze the available ACT UP webpages. The implications are immense: A group with the motto “Silence = Death” is sinking into the background, waiting to be noticed. Is ACT UP losing momentum and potential members?

The overall goal of this thesis is to provide a clear view of the gay rights movement leading to the battle against stigma in the form of extremist action groups like ACT UP. I intend to do much needed research in the area of the ACT UP Internet sites, as ACT UP is suffering from the overexposure of the public to HIV/AIDS information. This research will be the first of its kind, asking the questions of effectiveness of websites or organizations that have previously relied on active alliance and membership.
CHAPTER II

STIGMA AND MEDIA INVOLVEMENT

AIDS and Stigma

The AIDS pandemic has influenced and hindered the gay social movement beginning in the 1980s. While gays have battled for social equality throughout the 1960s and 1970s, the onset of HIV/AIDS in the early 1980s has interfered with the constant move towards equality. This chapter will examine the rhetoric of the gay rights movement from the late 1970s through the early 1980s and its media treatment in order to demonstrate the many ways that HIV/AIDS has affected knowledge, awareness, compassion towards, and treatment of homosexuals. The gay rights movement is easily placed into two eras: Pre-AIDS and post-AIDS. While the gay rights movement is easily classified as a movement, it is better placed into two distinct movements. This chapter will primarily discuss the post-AIDS movement and the roles that stigma and media involvement play.

Homophobia is an illness in itself. It is a fear of someone based purely on his or her sexuality, most often of gay men and of their sexual practices, i.e. anal sex. Both the general public and the government have been affected by homophobia, resulting in an almost crippling apathy regarding HIV/AIDS funding and treatment of people with AIDS.
(referred to as PWA’s). It is conceivable that homophobia has affected every aspect of HIV/AIDS. Discrimination against PWA’s who are not homosexuals is common, perhaps showing homophobia has affected even the PWA’s labeled “victims”, not necessarily homosexuals. The association of HIV/AIDS and homosexuality has promoted guilt by association.

The Public Media Center (1996) proclaims that “One-half to two-thirds of all Americans still condemn homosexuality or homosexual behavior as morally wrong or a sin” (p. 29). Pairing that statistic with the fact that “anti-homosexual attitudes have been shown to inhibit learning about the relatively low medical risks involved in possible AIDS transmission” and work in a counter-productive way, it is amazing that the general public knows anything at all about AIDS (Jelen and Wilcox, 1992, p. 730). Discrimination has run rampant, and although strict laws have been made since the late 1980s it is still occurring. In the workplace, PWA’s have dealt with dismissals, demotions, decreases in salary, and harassment. Even the healthcare they so desperately need has been denied. In the past, emergency calls from AIDS patients have been ignored. Healthcare providers have refused to administer needed medications. Insurance companies have refused to insure PWA’s. Even schools have forced children with AIDS to miss school while school boards develop AIDS-related policies. PWA’s have continuously been forced to use separate facilities (Herek and Cogan, 1996, p. 25). The list is endless. The stigmatization has stretched from the fear of homosexuals to all PWA’s. People are not discriminating in their discrimination.

The concepts of stigma and stigmatization are used to describe patterns of “social prejudice, discrimination, and rejection that are directed against an individual or
members of a group” (Public Media Center, 1996, p. 11). Homosexuals have been discriminated against by the Moral Majority, among many other groups, and to this day church leaders proclaim homosexuality as a sickness and a perversion. Adding to the battle against discrimination, the gay social movement has been blamed for HIV/AIDS. AIDS is not a well-received or well-understood disease. Often, ignorance is anything but bliss, and people either ignore what they fear or attach blame to construct a semblance of false understanding. This victim-blaming society has rested the AIDS pandemic upon the shoulders of the homosexual population. It appears that as the homosexual population was struck the hardest by the disease originally (in the United States), the straight public found the ideal scapegoat on whom to post blame.

Social change, defined as “any change, written or unwritten, in the way society regulates itself” is pivotal upon instrumental, symbolic events (Bowers, Ochs, and Jensen, 1993, p. 5). The gay social movement encountered resistance (without which there would have been no point to the movement itself) from the straight public precisely because of instrumental, symbolic events. The beginning of the AIDS crisis led to mass blame, the blame was based on pre-existing beliefs and attitudes towards homosexuals. Beyond stigma, the idea of a social movement is based upon shared beliefs that members of a group possess. Gusfield has determined a social movement to be broadly defined as “social shared activities and beliefs directed toward the demand for change in some aspect of the social order” (Hahn and Gonchar, 1971, p. 44). If, indeed, social movements are built upon shared beliefs, then the gay rights movement is built upon a shared belief that alienates straight society. The explicit use of language for AIDS awareness was an obtrusive barrier between the homosexual and straight populations;
"When you share urine, shit, cum, blood, and possibly saliva, you are at greatest risk of getting AIDS" (Bayer and Kirp, 1992, p. 34). The previous passage, from "Mother's Handy Sex Guide" which was distributed by AIDS project Los Angeles in 1985, is too explicit for general media use. Fox 5 News at 10 would, no doubt, reject it as a storyline. It was aimed at a gay audience by the gay media, and in using explicit language alienated the straight public from the possible education.

Another problem with tailoring the message to such a specific audience occurred when the gay population appeared to accept the blame due to the overwhelming response towards education and prevention by the gay press. The gay-as-guilty premise gained momentum in a series of steps. Many people wanted to believe it was solely a gay disease, whether it be for relief at having someone to blame or a moral mindset regarding homosexuality. The large response to AIDS by the gay community led to further blame for the disease. AIDS-related stigma is defined as either the fear of the disease itself or "symbolic AIDS-stigma", including fear and hostility toward those seen as most affected by or responsible for the disease (Public Media Center, 1996, p. 13).

Bowers, Ochs, and Jensen (1993) believe that "when social change is sought, agitators must approach the establishment to propose that change occur" (p. 20). This description of the petition stage occurred within the gay rights movement. Initially, there was the resistance of the straight public to the very idea of homosexuality. The pre-AIDS gay rights movement used the idea that awareness equaled acceptance, and attempted to become as recognized as possible. Attaching a face to "gay" was not completely liberating. For example, "banners in early gay pride demonstrations (before they became gay pride parades) read: 'Gay Sex, Gay Power'" (Bronski, 1996, p.1). The last
thing the straight public wanted to imagine was gay sex. In 1978, Harvey Milk, an openly homosexual city councilman, was shot and killed in San Francisco. The new Mayor, Dianne Feinstein, had said “the fact of his homosexuality gave Harvey an insight into the scars which all oppressed people wear...he believed that no sacrifice was too great a price to pay for the cause of human rights” (Kramer, 1989, p. 4).

The gay rights movement was moving towards equality. Its methods included decades of attempted exposure through public demonstration. In 1977 in Dade County, Florida, voters rescinded an ordinance passed by the county board prohibiting discrimination against gay people in housing, employment, and public accommodations. “It seems clear that for several years thereafter the gay rights movement was put in a defensive position as it focused on referendum battles over similar ordinances across the country” (Darsey, 1991, p. 47). The referendum campaigns across America held public attention and were the primary preoccupation of the gay rights movement until the early 1980s. The gay rights movement made gains by promoting the idea of equal protection for homosexuals in the “civil rights” vein. By describing homosexuals as a class of people who are denied equal protection under the law, the gay rights movement made a convincing case that persuaded heterosexuals without threatening them. Rather than bringing the visualization of homo-sex, they were entering the promulgation stage, where “agitators attempt to recruit members” (Bowers, Ochs, and Jensen, 1993, p. 20).

The shared activities and beliefs that Gusfield details are not aimed at “reinforcing followers, converting non-members, or pressuring decision-makers” but rather are the core and base of problems for the gay rights movement (Hahn and Gonchar, 1971, p. 45). The activities the gay rights movement has tried to incorporate
into mainstream America are the same activities the straight public finds disgusting and repulsive. The gay rights movement is not, however, aiming at converting the straight public to homosexuality. Rather, the activities of the movement are aimed at advertising "either to gain recruits or build sympathy" (p. 45). Why would a straight male give money to a gay charity for AIDS "victims" if he didn't see PWA's as victims, if he was afraid of homosexuals, if he thought homosexuals were responsible for HIV/AIDS, and if he didn't believe he could ever become infected?

The idea of "recruits" in the gay rights movement is legitimate and especially important in the post-AIDS movement. If stigma and stigmatization are overcome, then homosexuality will be able to come freely out of the closet. The concept of the closet itself defines gay sexuality as being hidden. When there is no longer reason to hide, the new recruits will consist of people who accept that they themselves are gay, as well as people who accept that others are gay. Building sympathy has been the anchor for the gay rights movement, weighing down homosexuals in the post-AIDS movement. There can be no sympathy for a group blamed for a hideous and deadly disease.

The Media Role in AIDS Stigma

The media have played a large role in the distribution of information. Television media is society's quick fix. People can see the pictures for themselves, and they come rapidly to ensure that people do not get bored. Many use television as a baby-sitter, to educate, and to entertain. Television is capable of so much as it reaches into millions of homes across the world, influencing people, affecting their conscious and unconscious beliefs and attitudes. It informs, reinforces, and changes opinions.
In treating HIV/AIDS solely as a gay disease, the straight media is losing the straight audience. Paula Treichler (1992) compares AIDS and network television to a monkey drawn to a paper bag and terrorized when it finds a snake (p. 17). The fear wears off the monkey, as Treichler (1992) claims AIDS reports have done for the public. The article centers on how to keep the audience watching (and understanding) despite the overexposure to AIDS media in the last few years. Those instrumental and symbolic events that the gay rights movement participates in, far from being effectual, alienated the straight public.

The 1990s were fraught with movement. Arguably, the social structure of the entire United States was moving to accommodate groups who wanted to be recognized as equals, resulting in the black movement and the gay rights movement in addition to many others. In an interview, Susan Sontag discusses gay rights from a media standpoint: "What has happened is that the complexity of gay politics from the 1970s to the early 1980s has become reduced to a stereotype that is based upon a handful of writers" (Zimmerman, 1995, p. 36). This stereotype has been many years in the making, and has been enforced by the "gay plague" of the early 1980s (Bayer & Kirp, 1992, p. 21). As time progresses, HIV/AIDS is being seen as an equal-opportunity pandemic, with the blame for its spread still resting on the homosexual population.

The media have played a key role in the public’s views and beliefs since the onset. Media treatment of AIDS affects the attitudes of the public, including the dual nature of the media as not only a transmitter of information and an influence in how the information is sent, but also as a recipient (or perhaps voyeur) of pre-conceived public notions and beliefs. While “news reflects and reinforces particular cultural anxieties and
concerns” there must be an existing public attitude for the reflection to take place” (Bird, 1996, p. 47).

Network television seems to be succumbing to and participating in the public apathy towards AIDS information. “It’s lost its market value” says a research director, proclaiming AIDS to be an old media sensation (Treichler, 1992, p. 140). Treichler (1992) insists that by breaking the stereotypes, AIDS media can begin to grab attention again, to make an impact. Gay media is listed as a good source of information for straight media to use also, however doubtful it is that the straight media will accept that input. Treichler (1992) has a strong belief in what the media is capable of, positive and negative, and includes a shopping list of “shoulds”. The networks should re-examine their visualizations of AIDS. They should turn to gay media for different views of AIDS. They should differentiate between risk groups and simple homophobia. Lastly, they should overcome the media slouch for AIDS by re-examining their language, and by renaming what are “acceptable” and “unacceptable” terms (p. 148). The media is a mixture of blessing and curse. It has the capacity to dispel myths and educate the general public, and at the same time it can reinforce stereotypes and add fuel to pre-existing biases. The post-AIDS gay rights movement bore the brunt of a negative spin on AIDS-related media coverage. Now, when the equal-opportunity nature of the disease is apparent, the media coverage is scanty and apathetic.

For many years sexual orientation has been seen as a black and white issue. In “The United States: At the Center of the Storm,” Bayer and Kirp (1992) discuss AIDS as “a tale of consensus-building across professions, political ideologies, and sexual preferences” (p. 7). The fact that HIV infection so disproportionately affected gay men
did much to affect the course of the response to the groups most heavily afflicted with the
disease changed the way the disease was treated; “AIDS is a disease of the socially
marginal: Gay and bisexual men, intravenous drug users, their sexual partners, and their
children. Blacks and Hispanics are significantly over represented” (p. 11). In marking
blame from the onset of the disease, the American straight public made a value judgment
that was both influenced and perpetuated by its beliefs about homosexuals. There was a
vicious circle, where gay rights had been denied by the moral majority, AIDS was
introduced in this country as a gay disease, and the public was given (or perhaps made
for themselves) another reason to fear homosexuals. As “homosexual acts were still
illegal in twenty-four states” and HIV/AIDS was perceived as a gay disease, the public
found little reason to support the victims (Bayer and Kirp, 1992, p. 13).

One of the first newspaper articles on HIV/AIDS appeared August 8, 1982 in The
New York Times. The author, Robin Herman (1982), writes of “a serious disease whose
victims are primarily homosexual men” (p. L31). At the time, two new cases a day were
being recorded at the disease control center in Atlanta, and the article “A Disease’s
Spread Provokes Anxiety” was placed in section “L”, in the back of the paper. The
media veered away from coverage of HIV/AIDS. Even after the original breaking of the
story, the media either left it alone or sensationalized it. For example, “Dr. David
Sencer, New York City’s Health Commissioner... emphasized that groups other than
homosexual men were involved” (Herman, 1982, p. 31). For one moment it seems as if
the straight population should be concerned about the spreading of disease. However,
“groups afflicted with the syndrome include more than 60 heterosexual men and women
who were drug abusers and used intravenous needles, 30 male and female immigrants
from Haiti, all heterosexual, and some hemophiliacs who use blood products to combat their illness" (p. 31). The middle-class, heterosexual, white population had no reason to assume this epidemic would ever reach them.

Language and Culture in AIDS Stigma

“Social movements make demands on society” according to Hahn and Gonchar (1971, p. 46). The lack of acceptance for the gay rights movement stems from societal beliefs regarding that group, as “movements are not ‘mere motions’ of being. They are always acts of man...and therefore languaging strategies” (Wilkinson, 1976, p. 92). Perhaps one of the true flaws of the gay rights movement was the language used for the media and from the media. There have been many discussions on the nature of AIDS, including the ways the public thinks about the disease and the meanings that have been attached to it. As discussed previously, Bird (1996) tells the story of a letter sent to Ebony magazine from a person signing her/himself “CJ, Dallas, Texas” (p. 44). The writer of the letter, CJ, claimed to be infected with the AIDS virus and having sex with four men a week in order to infect them. The letter led to a surge of calls to a radio talk show, which led to local and even national news coverage. It was later found that a 15-year-old girl, who wanted to raise awareness about the disease, wrote the letter. The story is cited as a product of oral folk tradition that has become transformed into “news.” Language is composed of arbitrary symbols, and “because of the nature of man, of language, and of movements themselves, all movements are essentially rhetorical, having historical, sociological, and other components defined according to the accidents of time, place, and circumstance” (Wilkinson, 1976, p. 92). Once again, the AIDS crisis was
affecting the gay social movement, through stigma, through negative media exposure, through language.

"Cultural researchers have sought to show that the line between news and legend is not really that clear" (Bird, 1996, p. 55). The media is shown to feed from rumor and folklore, and retell these stories as truth. Bird describes how the media are simply reflecting the concerns of the culture around them, "because the story reached so deeply into cultural fears and stereotypes, it took on a life of its own" (p. 54). AIDS representation in folklore literature is present in the form of jokes, legends, and other folk responses. Newspapers, magazines, television, and word of mouth all serve as vehicles for information; fact and fiction. Thus, the languaging strategies provided by the gay social movement in the late 1970s were rendered ineffective; "I am not interested in sin. I am interested in the difficulties people have in loving each other; I am also interested in how we use sex as a weapon..." (Kramer, 1989, p. 10). While the gay rights movement consisted of individuals struggling to be seen as equals, to be accepted and to have their actions become acceptable, the onset of HIV/AIDS and the concurrent blaming of the illness hindered and mutated their languaging strategies. While battling the already existing stigma of homosexuality itself, AIDS presented a new hurdle.

"Communication Practices in the Social Construction of Health in an AIDS Residence," an article by Frey, Adelman, and Query (1996), provides a framework for understanding how communication combines the medical, psychological, and physical worlds of disease. "The meaning of health is a contested concept where physical and psychological processes are intertwined with collective definitions of illness and well-being" (p. 384). The underlying ideas regarding "health" are broken down into physical,
psychological, and cultural loci. These perspectives are then placed into the context of a residential facility for people with AIDS (PWA's).

Frey, Adelman, and Query suggest that we use the term “disease” to refer to a person’s biophysical condition, while reserving the term “illness” to refer to a person’s subjective experience of his or her conditions. “All humans learn methods to monitor bodily processes and rhetorical idioms (verbal and nonverbal) to communication bodily states, including states of illness” (1996, p. 386). In living in a particular society we assume a particular “social body,” as a person’s experience with his or her body is labeled according to the social terms within which that person is embedded (p. 386).

“The conflict between the need to grieve the loss of fellow residents juxtaposed with the fact that extended or dysfunctional grieving can decrease the immune system’s capabilities,” or “depression bind,” is the idea used by the authors to explain the mind-body connection for PWAs. Interviews with facility residents display the myths and metaphors implanted in the language of AIDS as a disease and as a concept. While the experience of health and illness is rooted in the body, the way we discuss the experience in interpersonal and group communication lends new understanding to the bodily experience.

Our language itself gives an inside peek at the way we are thinking about AIDS. “In the description of AIDS, the enemy is what causes the disease, an infectious agent that comes from the outside” (Sontag, 1988, p. 17). Sontag (1988), in AIDS and its Metaphors proposes that the words used, far from being clinical, decry the “enemy” nature attached to the illness and groups associated with its spread. Phrases such as “the invader is tiny...,” and “single-mindedly, the virus ignores...” affix human
characteristics, feelings, emotions, and thoughts to a disease. According to Sontag (1988), "saying a thing is or is like something-it-is-not is a mental operation as old as philosophy and poetry, and the spawning ground of most kinds of understanding, including scientific understanding, and expressiveness" (p. 5). Although metaphors are a means of thought, the author reiterates that there are some metaphors which would be better left unused. One such metaphor is the principle metaphor of "plague". The concept of "plague," according to Sontag (1988), is regarded as a judgment on society, and "the metaphoric inflation of AIDS into such a judgment also accustoms people to the inevitability of global spread" (p. 54).

The real problem for the gay community lies in the blame for the disease. The gay rights movement has relied on metaphor and abstraction for the straight public to attend to its messages. Discussing anal sex and sex acts of man/man or woman/woman would not further the movement. In all truth, providing images of what the gay community is trying to make acceptable would have a very negative impact. During the promulgation stage of movements, agitators attempt to recruit members. "One of the main purposes of promulgation is to win public acceptance of the agitators' ideology, their system of values and beliefs, and their policies" (Bowers, Ochs, and Jensen, 1993, p. 21). The ideology of the gay rights movement is simply that homosexuality is a fact of nature that cannot be denied. Their system of values and beliefs is no different from the rest of mainstream America. They ask not for special treatment but rather equality across social and political policy. It is language that can change a battle for equality into a battle for or against anal sex.
The rhetoric of a movement has been established as the primary ground for communication within that movement; “out of the vocabulary if motives employed by movement members collectively and individually, a definition of the particular ordering and re-ordering aims of a given movement may be obtained” (Wilkinson, 1976, p. 94). The gay rights movement had to re-order and re-group as time progressed, as all movements must. However, the reasons for the changes were different than those most movements face. The beginning of a disease also marked a new beginning and a new struggle for the gay rights movement.

AIDS changed the policy landscape: “AIDS, a lethal disease transmitted in the most private settings, would test the vitality of the jurisprudence of privacy, the durability of the commitment to individual rights and due process, and the capacity of those responsible for the defense of the public health to adjust their professional traditions…” (Bayer and Kirp, 1992, p. 8). Considering the pre-AIDS gay rights movement struggled against stigma and stereotyping, the post-AIDS movement added to the load. Public health policy began with the idea that AIDS was a gay disease, affecting only the most marginal of populations. Bayer and Kirp (1992) believe that “the early framing of AIDS as exceptional – requiring a unique set of measures” is gradually giving way to a shift in the ideological focus of policy debates (p. 10). AIDS is becoming seen as mainstream. The beginning of the gay rights movement was marked by homophobia and stigma. The introduction of AIDS was marked by homophobia and stigma. Media coverage has been marked by homophobia and stigma. While the intent to provide information may have been sincere, the type of information being provided was based on blame of a homosexual and marginalized group. The general public, who often avoid contact with
homosexuals and AIDS victims, have long assumed that ignorance is bliss. "Crisis often begets extremism" (McLaughlin, 1967, p. 206), which leads the gay rights movement into the next chapter: Larry Kramer and AIDS Coalition to Unleash Power. The gay rights movement was introduced to and then blamed for HIV/AIDS, the ultimate crisis. A movement that started out fighting for basic human rights and equality then took on responsibility for nearly two decades of death.
CHAPTER III

AIDS COALITION TO UNLEASH POWER

Identity and Unity or Fragmentation?

AIDS Coalition to Unleash Power (ACT UP) was created in 1987 by Larry Kramer. His stint with Gay Men's Health Crisis in the early 1980s had not ended happily, and Kramer had not reached his goals of education and prevention. While he may have been a skillful organizer, his personal politics and abrasive manner have made many of his own group members dislike him. ACT UP was Kramer's second attempt to create and maintain a health organization aimed at preventing AIDS by educating the public, and his languaging, or rhetorical, strategies made it difficult for the public to ignore.

Rhetorically, ACT UP has been at the forefront of many political and social storms; "Gays in general have been caught up in a mobilization movement for more than two decades; AIDS has been one part of that movement" (Jennings and Anderson, 1996, p. 324). However, as time has progressed and as the AIDS pandemic has waxed and may be waning, the nature of ACT UP has changed. This paper will first pursue questions regarding the languaging strategies of ACT UP. Kramer, the leader of the coalition, will be discussed as an enabler and also as a debilitator. Throughout Kramer's rule as the god-figure for ACT UP, the goals and nature of languaging strategies changed. Post-
Kramer, ACT UP shows a distinctly different form and function than did the original chapter of ACT UP.

Obviously, the gay and lesbian movement strongly influenced ACT UP since the majority of its members are self-identified as either lesbian or gay (Elbaz, 1990, p.50). In an interview, Bonnie Zimmerman discussed gay rights from a media standpoint; “What has happened is that the complexity of gay politics from the 1970’s to the early 1980’s has become reduced to a stereotype that is based upon a handful of writers” (Sayer, 1995, p. 36). Larry Kramer (1989) himself may agree. He muses "can it be, I have begun to wonder, that gay ‘political’ press and critics are out of touch with the realities of their audience and their lives? Can it be that these critics are writing for a very small group, quite possibly only each other?” (p.17). Indeed, Kramer himself is guilty of catering to a small audience; “Even straights with a bent for confrontation may have felt excluded from more confrontational groups and their activities” (Jennings & Andersen, 1996, p. 324).

The formation and rehabilitation of ACT UP can be discussed in relation to Leland GrifSns’ (1952) guidelines for movement development. Griffin (1952) lays out the three phases of development as being (1) “a period of inception...when some striking event occurs...and is itself sufficient to initiate the movement” (2) “a period of rhetorical crisis...the initiation of new arguments or merely through the flooding of existing channels with a moving tide of discourse” and (3) “a period of consummation, a time when the great proportion of aggressor rhetoricians abandon their efforts” (p. 368). This clarification by Griffin counts toward only a bare skeleton of the gay rights movement
and provides an basic framework for the reader to comprehend the stage in which ACT UP appears in the gay rights movement.

Using the second stage of Griffin's guidelines, ACT UP is flooding existing channels with a “moving tide of discourse” (Griffin, 1952, p. 368). Combining a conceptual framework provided by James Darsey (1991), ACT UP can be perceived as a group operating from a belief in unity and achievement. “Unity is the most prominent value appeal” claims Darsey (1991, p. 48). If, indeed, ACT UP is attempting to flood existing channels (including the Internet), then unity within the group should be an important aspect to examine. Another prominent appeal provided by Darsey is achievement, and, in a sense, it is at the core of the discourse. ACT UP is centered in achieving success in educating the public. The question in analyze is: Who does the “public” consist of?

ACT UP and Larry Kramer

ACT UP was created in early 1987, to prod scientists to speed up the release of AIDS drugs, to humiliate and harass government officials, and to generally promote awareness through any means necessary (Getlin, 1990, p. 4). ACT UP, with Larry Kramer, began a campaign to promote awareness using the logo “Knowledge = Power”. The immediate goal of ACT UP was to make the public, gay and straight, aware of the life-or-death business affecting the three-quarters of a million Americans infected with the AIDS virus. The logo then expanded to include yet another strong motto: “Silence = Death.”
Knowledge equals power. Jensen and Hammer back (1980) would argue that a strong term will show that "the group should become one against a common foe" (p. 196). The words "knowledge equals power" move towards constructing an enemy in ignorance. A main function of AIDS Coalition to Unleash Power is to shove information into the faces of those who would rather close their eyes; "ACT UP is a grass roots organization dedicated to the principles of non-violent civil disobedience as a means to force the government to address the AIDS pandemic" (Women Alive, 1996, p. 1). The motto and general languaging strategies will be discussed more in-depth later in this paper.

Kramer (1997) complains about gays as "the only minority that never writes about our oppressors" (p. 64) and uses the logo "Silence = Death" to make a point about those oppressors. Who is that common foe? The Moral Majority has long been a silencer of gay rights and "its aim...is not to join us to the majority but to lose us in the majority. But in no way are we part of the majority because the majority denies us just about every legal avenue that could lead us to being just like them" (Kramer, 1997, p. 68). Is justice being served? Darsey (1991) points out that "gays often urge each other to exercise their influence in the political arena by voting, lobbying, and writing to elected representatives" and yet Kramer has gone far, far beyond a simple search for justice (Darsey, 1991, p. 56). Rather, Kramer (1999) has made devils out of government and state officials and, through a powerful use of language, has promoted an anger and backlash against public policies regarding AIDS. "Our job is not to be invited to coffee or schmooze at a cocktail party. Our job is to make change happen as fast as possible and direct action works for that." A recent quote taken from a website for ACT UP
(1999) (http://www.actupnv.org/) shows the intentions of the group. ACT UP has gotten a fair share of negative attention, much of it brought on purposefully.

The use of inflammatory languaging strategies, combined with the visibility of the group and its logos has prompted government officials to protect themselves from the verbal and often symbolic assaults. An ACT UP speech at an AIDS conference, posted on the internet, claims that “The governments of the world are killing people with AIDS” and “hatred of the poor and of the disenfranchised communities continues to allow discrimination, stigmatization, violence, and even the murder of people living with AIDS to remain unchecked” (Riley, 1996, p. 2).

Beyond the languaging strategies, Kramer was an expert at restructuring experienced reality. His forceful nature and verbal aggressiveness caused him to be hated by many, and noticed in the process. Kramer (1997) took every opportunity to stand on his soapbox and proclaim all that is unfair in the world. He complained that “after all our history, after all these deaths, we don’t have a gay culture. We have our sexuality, and we have made a culture out of our sexuality, and that culture has killed us” (p. 65). Beginning with Gay Men’s Health Crisis (GMHC) Larry Kramer attempted to promote awareness in any manner possible, and was denied that right due to the manner in which he attempted to impart his message.

Within ACT UP, Kramer was able to construct a shared reality; a restructuring of the way gays thought of themselves and their culture. By speaking out in a time when nobody wanted to hear or listen, Kramer opened a new reality and a new way of thought for gays. Building sympathy has been the anchor for the gay rights movement, as there can be no sympathy for a group blamed for a hideous and deadly disease. The reality
was that of marginalized groups blamed for AIDS. The 1980s were a time of finger-pointing and harsh blame: "The straight world is scared now because they’re worried it’s going to happen to them. What if it doesn’t? If all this lethargy is going on now, think about what will happen then - just as you are coming down with it and facing death" (Kramer, 1989, p. 172). Kramer attempted to point out that even while the straight public began to realize that the disease may affect them, they engaged in little or no preventive behavior, and avoided any kind of discussion or information related to the topic of AIDS.

Inflammatory Language and Collective Voice

McEdwards (1968) claims that “with extreme action as their goal, they (speakers) have found they succeed only when using language that is also extreme. Concrete diction heavy with unpleasant connotation appears; unexpected vocabulary upsets the listener’s expectations of the speaker and of the occasion” (p. 37). Larry Kramer (1989) has stepped up to the AIDS battle, against authority and against his own group members, and said “What the fuck is going on here, and what the fuck are you going to do about it?” (p. 171).

ACT UP employs tactics of verbal and nonverbal obscenity to confront people and organizations who have hindered the fight against AIDS, and also attempts to gain media attention whenever and wherever possible. Kramer points out that “the lesson I learned from ACT UP is: The more they’re afraid of you, whether real or perceived, the more you can get done” (Winokur, 1994, p. 35). The most overt organizational feature of ACT UP was its focus on the emotion of anger, an emotion that was evoked to unite its members. As its mission statement declares: “ACT UP is a diverse, nonpartisan group
united in anger and committed to direct action to end the AIDS crisis” (Ariss, 1993, p. 19). Unity, as a focal point of any organization, played a large role in the effectiveness of ACT UP. Being involved in an organization, any organization, means participating in that specific group. An editorial from the Philadelphia Gay News is illustrative. “Bryant Threatens All GAYS!” reads the headline. Referring to the anti-Bryant forces in Dade County, the editorial admonished the reader: “Florida gays are doing all they can, but that is not enough. We must help. Otherwise, Anita Bryant and friends might show up in your town” (Darsey, 1991, p. 54). “We” statements imply “that the issue is the concern and responsibility of both the speaker and the receiver(s) of a message” as printed in an interpersonal communication text (Adler, Rosenfeld, Towne, and Procter, 1998, p. 156). Darsey (1991) points out that “gay publications, though identified with their places of origin, often have a national circulation and provide national and international coverage” (p. 48). One then wonders how Larry Kramer can become embittered about a lack of collective culture.

The start of ACT UP was promising. A very large number of ACT UP members came from other social movements, bringing with them both organizational and analytical skills. Larry Kramer himself had years invested as a founder of Gay Men’s Health Crisis, what had become his albatross. “Those members brought many years of activist experience, sharing their language of resistance and their critique of traditional boundaries” (Elbaz, 1995, p. 46). Due to these prior experiences, the group was better able to fulfill the period of rhetorical crisis, whereby it did, indeed, attempt to engage in the “flooding of existing channels with a moving tide of discourse” as Griffin outlined (1952, p. 368).
Historically, ACT UP has drawn its strategic effectiveness from working outside the system. Activists “deplore the slow pace of the political process in the United States, which makes it unable to accommodate the urgencies of the HIV/AIDS epidemic” (Elbaz, 1995, p. 65). “Direct action”, as the Internet site at actupny@panix.com declares, usually happens with the intent of achieving media coverage. ACT UP has created sensationalistic events to stir public sensitization. Through ACT UP’s direct action strategies, the media have paid much attention (positive and negative) to the languaging strategies, and also the “biomedical arena that otherwise would have remained unnoticed” (Elbaz, 1995, p. 66). While fighting a disease living inside human bodies, ACT UP has been fighting a verbal and symbolic war with relational messages beyond the simple content of the words used.

ACT UP - Past

Starting on March 24, 1987, ACT UP used brash tactics seeking to publicize the plight of AIDS victims. In 1989, under the reign of Larry Kramer, a rally organized by ACT UP attracted more than 2,000 people to City Hall in New York. At St. Patrick’s Cathedral in 1989, protesters from ACT UP and other groups chained themselves to pews during Mass, shouting and lying down in the aisle and “drowned out Cardinal John O’Connor’s sermon with shouts of ‘bigot’ and ‘murderer’, and desecrated the Eucharist” (Coleman, 1991, p. 533). Also in 1989, ACT UP members interrupted trading on the stock exchange floor, “handcuffed themselves to the balcony railing, blew foghorns, and unfurled a large banner urging traders to sell Welcome stock because the company was charging astronomical amounts for the drug AZT” (MENCHIN, 1992, p. 39). In 1991,
ACT UP members broke into the studio of "CBS Evening News" and one activist managed to jump in front of a camera at the beginning of the broadcast.

Darsey (1991) points out that after the AIDS crisis affected America, "justice was consuming equal attention rather than unity" (p. 56). Gay Men's Health Crisis was little more than a stepping stone, or a learning experience, for Larry Kramer. He practiced his skills at organization and fought for some semblance of justice within the AIDS pandemic. Kramer was ousted from the group for his use of derogatory and inflammatory language, and is not considered a well-liked individual by any means.

When hearing that GMHC was asking for a new building to use as a home base (rather than using the money to help more People With AIDS, or PWA's) Kramer (1993) said "When I hear things like this, I want to throw shit pies in their faces and scream so loudly that their fucking eardrums will break" (p. 80). It appears that Kramer was unable to control his own creation, leading to a form and function within his own group that he greatly disliked and, in turn, the group began to rally against Kramer himself. Kramer had goals that were not congruent with the group he had formed, and in creating ACT UP he was attempting to revisit the goals he had originally laid out.

What of these goals? The goals of Larry Kramer acted out through ACT UP must be divided into two categories: Perceived goals and presenting goals. Adler, Rosenfeld, Towne, and Proctor (1998) use the terms "perceived self" and "presenting self" to discuss impression management (p. 122). ACT UP is a public organization, and the definitions apply. Perceived goals are reflections of the group-concept. These goals mirror who they believe themselves to be in moments of honest self-examination. Presenting goals
are the public image, the way they want to appear, and sometimes unintentionally appear to others.

There should be no question that the ACT UP agenda is filled with unfinished business. Even on the ten-year anniversary of ACT UP, Kramer was still calling his enemies (perceived as devils) among AIDS experts and public officials “irredeemable pigs” (http://www.jeffstryker.com/actup.html). ACT UP has had battles with the Moral Majority (amongst others) since the day the group was founded. The video “Stop the Church” shows the strategy sessions in which ACT UP planned the “die-in” at St. Patrick’s Cathedral in 1989. “It mocks the cardinal and the church and misrepresents the church’s views of people with AIDS and the AIDS crisis” (Coleman, 1991, p. 533). The original New York chapter spawned sister organizations in other cities, some of them overseas, and the group continued to bring the issue of AIDS to center stage by acting out in the same manner listed earlier.

Making a how-to video, “Stop the Church” falls under perceived goals. The motto which stuck with ACT UP for the longest amount of time is Silence = Death. Indeed, Larry Kramer perceived a major goal of ACT UP to be visibility. In the past and present, the Catholic Church has been outspoken against homosexuality and was a forerunner in placing blame of AIDS on the homosexual population. Larry Kramer, in moments of honest self-evaluation, formed ACT UP to make it known that AIDS was spreading because, as Kramer (1997) puts it, “nobody is out there saying loud and clear and nonstop: Stop acting like assholes. Start acting like adults”, a presenting goal (p. 59). The church, with opposing viewpoints and a huge following, was exactly the target Larry Kramer had in mind when he formed ACT UP. In fact, “Stop the Church” was not
aired by PBS at that time. John Grant, a vice-president for Public Broadcasting Service’s said “Stop the Church” did not meet PBS standards for broadcast quality and that it was “inappropriate for airing because its pervasive tone of ridicule overwhelms its critique of policy” (Coleman, 1991, p. 533). The languaging strategies and direct action techniques failed to get the media exposure that ACT UP hoped. The rhetoric of the tape is neither positive nor constructive criticism of the church and AIDS, but is rather a negative spin with the church being made to seem “arrogant, sterile, fundamentalist, patriarchal, homophobic, racist, hypocritical, a purveyor of hate” (Coleman, 1991, p. 534). “Stop the Church” was not aired until KCET finally succumbed to the pressures and the media exposure to the Catholic Church bashing of the tape mixed with the encouragement of the gay community. While Kramer may have perceived any media attention to be good, ACT UP did not always leave a positive impression on the general public.

Who, indeed, was Kramer’s audience? The gay media latched onto the ACT UP antics, and the straight media reported with a negative tone. The issues were addressed: they were not emotionally available to the majority of the public who had never had family or friends die from the disease. Instead, the negative media attention led to an increase in fear and avoidance of ACT UP even by the gay community; “and anyone who is targeted by protest knows another set of emotions: shame, feeling like a failure, anger at being singled out, sadness that one’s own people are angry, and - hardest of all -  pain from the truths often resonant in ACT UP’s critiques of gay and lesbian leaders” (Vaid, 1997, p. 88). Kramer had taken the idea of the battle against AIDS too far, it seems. While the perceived goals of the group were to educate as many people as possible while targeting specific powerful groups and corporations to encourage better treatment of
People With AIDS (PWA's) the presenting goals often came across to the public as abusive, horrific, and morally outrageous. “ACT UP was driven by the pressure of survival to adopt an ends-justify-the-means mentality” and the question is: Where is the end? (Vaid, 1997, p. 88).

ACT UP - Present

“I didn’t want to fight anymore with my own people,” Larry Kramer says, “I was depressed. I think the battle against AIDS has been lost. I think millions of people are going to die” (Getlin, 1990, p. 1E). By 1990, Kramer had already become estranged from ACT UP. In only three short years, he had gone from founding a group he hoped would change the nature of AIDS treatments medically and socially from the stigmatized gay plague, and instead he stepped down as a leader and chose not to go to the Sixth Conference on AIDS in San Francisco, 1990. The presenting goals of the group had changed from what Kramer had wanted for himself, and just as Gay Men’s Health Crisis ousted Kramer for his harsh manner and debilitative languaging strategies, ACT UP became his second perceived failure.

ACT UP has continued to function without Larry Kramer. It has branched off into many other sister organizations and no longer engages in quite the level of extreme action for which it originally became known. Kramer has said “When I started ACT UP, I hoped that we had started a worldwide movement. I was conscious of the fact that I had these troops there. I can’t say ‘at my disposal’ because the problem with ACT UP was that it wasn’t at anybody’s disposal. It was democratic to a flaw” (Winkokur, 1994, p. 32). Perhaps Larry Kramer’s disenchantment with ACT UP has been that he does not
believe in democracy for those who step outside his firmly-set beliefs. It seemed at times that Kramer played the role of a debilitator for the group, and as such he is now merely an outsider, watching his own efforts as a bystander.

It is important to note the apparent apathy in ACT UP today. While in the past ACT UP was socially active and often extreme, there was no gradual segue between the outrageous acts and languaging strategies from ten years ago and the quiet, almost absent, presence currently. The upcoming section “Internet Effects and ACT UP” discuss in-depth the information that is currently available on the Internet. In fact, this is the only information available today, short of visiting ACT UP chapters across the United States. ACT UP is not acting up, but is rather allowing the Internet to be a passive carrier of information.

The changes in ACT UP were sudden and surprising. Larry Kramer may have been perceived as abrasive and as an unfit leader, but the group remained active while he was acting as a head to the organization. Once Kramer was driven out of his organization, it became quiet and staid. While each chapter has many less powerful leaders, it seems that the group ruling has proved ineffectual. The simplicity and magnitude of reach of the Internet proved to be a downfall for ACT UP, shown by the lack of action and appearance in the last five years. It seems to be an immediate downslope from the direct action of Kramer to the Internet-centered public relations tactics of the current ACT UP chapters.
CHAPTER IV

AIDS COALITION TO UNLEASH POWER: MAIL AND THE INTERNET

Internet Effects and ACT UP

As Strate, Jacobson, and Gibson (1996) have pointed out, “the emergence of cyberspace...might be seen as the single greatest reversal in human history of the trend to centralized social control” (p. 52). In discussing the content of web pages for ACT UP, the concept of iconic writing comes to the forefront, the “reemergence of the perceptual out of prose” (Strate, Jacobson, and Gibson, 1996, p. 111). The written word has proven to be a powerful medium and may now be replaced with images, via the Internet. Has the availability of information and images on the Internet changed the goals or actions of ACT UP? While the extreme actions of ACT UP are in the past, what of the inflammatory languaging strategies? If, indeed, “it is the breakout of the visual that leads to new constructions of the self” then has ACT UP experienced a redefinition of itself through the use of the World Wide Web? (Strate, Jacobson, and Gibson, 1996, p. 112).

There are two sides of the Internet as a communication medium. The first discusses the merits of print communication, in that “print emphasizes and rewards the individuality and uniqueness of the author” and that “in subordinating images to words, print technology encourages a rhetoric in which abstraction is privileged at the expense
of the senses and sensory information” (Strate, Jacobson, and Gibson, 1996, p. 111).

The second side would argue that “there is a tacit assumption that perceptual presence can replace words, or indeed symbolic representation altogether” (p. 110). Indeed, electronic technology is changing the communicative balance between words and image.

The web pages of ACT UP show a fine balance of words and images, mirroring a basic communication structure of verbal vs. nonverbal communication. Verbal communication consists of three elements: Spoken words, written words, and sign language (Adler, Rosenfeld, Towne, and Proctor, 1998, p. 173). Adler, Rosenfeld, Towne, and Proctor (1998) describe the functions of nonverbal communication (such as pictures within web pages). Nonverbal communication may repeat, substitute for, complement and accent, regulate, or contradict verbal communication (p. 181). Each web page promoted by ACT UP has a mix of verbal (written words) and nonverbal (images) which can promote multiple messages through one channel; the Internet.

The general public has access to the Internet. Small children are becoming quite comfortable “surfing” web pages and finding information they need and want. ACT UP has many cyber pages dedicated to the ongoing fight for equality and educating the public about AIDS. The original New York chapter of ACT UP has splintered into so many sister organizations that it is nearly impossible to track each specific branch through websites. Rather, websites considered for this paper contain general information on ACT UP, with a listing in the heading and hyperlink on America Online (AOL).

The sites selected include the site for ACT UP / GoldenGate, ACT UP Philadelphia, and ACT UP / New York, the founding branch, all of which are comprised of hyperlinks and text (see appendices).
The websites for the three chosen ACT UP chapters are remarkably similar. The websites were accessed in June of 1999 and again in January of 2000 to monitor changes and updates on the sites. Each website is in simple black and white, with the ACT UP logo displayed near the top of their website. In this study of discourse on the Internet, the target audience and goals of the senders are identified by analyzing language and pictures available on each site. Also, the messages will be examined in terms of symbols, usage, visual appeal, interactivity, and persuasive impact (Schultz and Barton, 1998, p. 6). In evaluating content, the following questions are posed: What is the purpose of the web page? Who is the audience? Is the document visually appealing (i.e. interactivity, shock value, colors)? Finally, are the graphics and art merely decorative or do they serve a specific function (Grassen, 1996, esthere@library.ucla.edu).

ACT UP / Golden Gate (see appendices) has a remarkable image of a devil-like creature screaming, placed on either side of the “to contact us” box in the middle of their website. Below the images is the sentence “Welcome! Please choose from the following options”; a friendly site, other than the screaming devil creatures. The target audience on this site is not easily recognizable. If one did not know, prior to entering the site, that this was a site for an AIDS organization, it would not be immediately obvious. The word “AIDS” is mentioned only once on the entire page. The options to choose from (verbally) are “About us,” “Abstracts & Reports,” “Contact other ACT UPs,” “News Releases,” “Writer’s Pool articles,” and “Testimony.” The audience may be, in fact, gay men searching for information on HIV/AIDS and the medications involved. However, this web page isn’t centered on sexuality or even action, but rather asks “Trouble with Protease inhibitors?”
The interactivity of the Golden Gate site is fair. It provides links for the viewer for specific information about the group, abstracts and reports, information needed for contacting other chapters of ACT UP, news releases, writer’s pool articles, and testimony. The site is, overall, quite sparse and the space is used without being cluttered. As for shock value, despite a lack of color, the pictures at the top are an attention-grabber which are at odds with the friendly nature of the rest of the site. The motto “SILENCE = DEATH” sits atop each screaming devil picture, with the ACT UP Golden Gate logo underneath. Every picture on the site, with the exception of the screaming devil pictures on the top, provides a link to another area of the site. All of the pictures are generic and plain, for example the hyperlink to “Writer’s Pool articles” includes a tiny picture of a newspaper. In addition, the site has not changed in any way from the 1999 version to the 2000 version.

ACT UP Philadelphia (see appendices) is poorly made and does not use the space afforded to them for the site. There is a great deal of white space, and the images are smaller than need be. There is a box entitled “Contact Information” detailing when and where that specific chapter meets, but there is a lack of information on the group itself: goals, initiatives, AIDS information. There are a few hyperlinks to other ACT UP sites, most of which are within the United States. Overall, this website is functional without being interesting and without involving the viewer. The only remarkable graphic on the page was a moving banner with the words “OVER OUR DEAD BODIES” written on it. The phrase is not a typical ACT UP logo, and its meaning is not explained on the page. The page has changed from the 1999 version to the 2000 version. However, the changes consist only of a change in font on the heading of the site with the ACT UP logo and the
addition of meeting information. While ACT UP was originally in a balloon font (somewhat soft and fluffy-looking) it is now, in 2000, slightly smaller and in solid, bold font. Underneath “ACT UP” is written “ACT UP Philadelphia” in slightly bigger font than in 1999. In the 1999 version, there was a large amount of white space in the middle of the page. Currently, there is a blurb regarding meeting times at St. Luke’s Church, with directions on how to get there. While the other information on the site is centered towards the middle, the new information is set to the left, and appears messy and unorganized. This site does not appeal to any one audience. It is, in fact, very generic and doesn’t appear to be targeting anyone in particular (unless they need directions to St. Luke’s Church.)

ACT UP New York (see appendices) was the founding chapter for the organization. This website is more involved than the two previously discussed, with more graphics, an increase of powerful language, and more hyperlinks leading to interestingly-labeled sites. The page was again done in black and white, a trend in ACT UP websites (and perhaps easier to make). The text in the middle of the page reads “ACT UP is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis. We advise and inform. We demonstrate. We are not silent.” Underneath these words is one of the most-used ACT UP logos: “Silence = Death”, displayed in white on a black background, with the logo forming a triangle (the gay pride symbol). The page includes hyperlinks to sites containing information such as “Clinton ZAPS”, “Research for Women”, and “Youth AIDS Zine.” The page is appealing to a more specific audience than the previous two, if only because it provides information relevant to specific age groups and sexes. There are no disturbing graphics,
just a powerful use of the originally used ACT UP slogan "Silence = Death". This site makes good use of a mixture of graphics (including many hyperlinks) and written statements. While there have been changes made from the 1999 to the 2000 version of this site, those changes are minor and, as with ACT UP Philadelphia, consist only of changes in font.

None of the three sites discussed is very interesting or grabbing. While the information is there and may be accessible, it is not appealing to any specific groups of people, nor is it immediately apparent what the site is "selling". There are many reasons why the sites may be plain and unchallenging, including the problems involved in presenting explicit messages in public space (Internet) and the difficulty in focusing on changing private behaviors that cannot be observed and are sometimes illegal (Edgar, Fitzpatrick, and Freimuth, 1992, p. 92).

While mainstream America may have access to the World Wide Web, these pages should be aimed at a specific audience. The pages are not easy to find, and the search on America Online will not process a request for "ACT UP", rather the name AIDS Coalition to Unleash Power has to be written out, along with a specific chapter. The pages are not updated frequently, as is apparent in the lack of change between the year 1999 to the year 2000, although one of the ineffectual leaders of ACT UP does check the E-mail about once a week and is prompt in sending information, no matter how sparse, out for those who request it. While ACT UP may advertise direct action, the pages show the opposite: A group which has settled down throughout the years, and which isn’t involved in extremist action to the extent it used to be. Post-Kramer ACT UP shows a very different form and function than did the ACT UP Kramer began in 1987. The
Internet may be an excellent vehicle for mass amounts of information, yet ACT UP does not utilize the web to the capacity they could. The shock value and availability of information simply aren’t there. Also, the web pages have neither a detailed (or even scant) history of the gay rights movement nor a hyperlink to areas of information on the gay rights movement.

**ACT UP San Francisco - By Mail**

Within one month of E-mailing ACT UP San Francisco (at actupsf@aol.com), I received a large packet including information about HIV/AIDS, treatments, and the medical community. Much of the information was sensationalized and used scare tactics to gain the readers’ attention. The headline of one article read “Drugs No Cure for HIV - Therapy is Seen as Doomed.” There was also a plethora of fliers included, denouncing a number of public officials. These fliers will be analyzed according to these questions: Is the flier visually appealing? Do the graphics and art serve a specific function? Is the information aimed at a specific audience? Finally, are there ways to contact the group with responses to the information being presented (Grassen, 1996)?

All of the fliers are visually grabbing without having high-quality graphics. All three are two-sided, with large amounts of printed information on the back, explaining the picture and headline on the front of the flier. The first flier chosen is aimed at degrading Anthony Fauci, who has overseen government sponsored trials that test combinations of immunosuppressive therapies (see appendices). The second flier includes pictures of former governor Pete Wilson, U.S. Senator Jesse Helms, and attorney Dan Lungren, with the caption “1995 World Series of AIDS BIGOTRY –
Trading Cards” (see appendices). The third flier has a picture of Pat Christian of the San Francisco AIDS Foundation, with Christian made to look like a cat (see appendices).

Anthony Fauci is on the front of a flier (see appendices), shown on a green background with a bad (yet recognizable) likeness, made to look like a puppet with dollar signs on his forehead. The graphics are well-done in that they relay the point of the flier immediately. The background is of AZT and d4T pills, with Fauci’s head forming the middle of a skull and crossbones. The headline reads “MURDERER, LIAR” and at the bottom it reads “& DRUG COMPANY PIMP.” The flier is extremely visually engaging, if not appealing. The graphics and art serve the function of telling a story about someone who ACT UP has targeted as a devil, which is reiterated on the back of the flier. The information is aimed at the audience of people who are interested in ACT UP, which could include supporters and dissidents. This particular flier did not have an address, phone number, or E-mail address printed on it. However, it did come in a packet with many other pieces of information containing ACT UP San Francisco’s address. The flier is extremely effective at relaying the message it intends to send.

The second flier studied (see appendices) has pictures of Pete Wilson, Jesse Helms, and Dan Lungren, all slightly distorted. Each character is placed in the center of a baseball card frame, with the flier itself entitled “1995 World Series of AIDS Bigotry.” The ACT UP SF logo is unobtrusive in the upper left corner. The blurb underneath the characters begins “Hey kids, it’s open season on people with AIDS! Grab your bats and be just like your fag-bashing heroes!” The bottom of the page proclaims that we should “GET ‘EM ALL!” This flier is by far the most professional-looking as well as the wittiest. The back of the flier is composed of 6 paragraphs about the Republicans Helms,
Wilson, and Lungren and the damage that ACT UP perceives them as having done to the HIV-infected communities.

This flier is in yellow, with black print. The graphics look professionally done, and are stimulating and disturbing in relation to the copy presented. The graphics and art serve the function of portraying these three men in a negative light; mocking them for their election practices and choices. The baseball analogy compliments the good old boy image portrayed often by the Republican party, especially in AIDS-related topics. ACT UP has primarily centered its efforts on government officially and larger companies, and this is no exception. The information is aimed at gays and lesbians, and is promoting ACT UP’s efforts to stop oppression. As the flier says “Experience the excitement of oppressing gays and lesbians. Feel the thrill of driving an HIV infected community into an early grave.” ACT UP San Francisco places its street address, telephone, and e-mail address on the back of the flier.

The third flier examined (see appendices) was aimed at a specific person, Pat Christian of the San Francisco AIDS Foundation. Apparently, ACT UP SF did not agree with Christians decision to exclude media from the 8th annual Leadership Recognition Dinner by stating it was needed to protect the “anonymity” of the leaders and attendees. ACT UP is disgruntled with Christian because a main focus of the group is to be as visible as possible.

The flier is in hot pink, with Christian’s face spotted and whiskered to look like a cat. The headline reads “AIDSPHOBIC, UNION-BUSTING SFAF EXEC GETS PAID SIX-FIGURE SALARY” while at the bottom “DUMP FAT CAT PAT” is written. The back of the flier is all printed information about Pat Christian and her actions that ACT
UP does not agree with. The flier is the least visually appealing of the three. The graphics aren't as morbid or angry as the others, and the language isn't as harsh or abrasive. The information may miss its target, as Pat Christian isn't as well known throughout cities other than San Francisco. The flier has an address, phone number, and E-mail address printed on the bottom of the back side, making for easy access to ACT UP SF.

Each of the fliers has a specific purpose, carried out well by the graphics and use of language. While ACT UP may not be participating in direct action as often as they did in the late 1980s, they are active in indirect ways, and provide much information on the topics they feel are important. The quieter, more docile way of approaching public officials may be more effective as a tool for compliance, as there is no threat of violence. There is virtually no mention of the efforts of past ACT UP members or the gay rights movement on any of the web pages.

Conclusion

This study provided a solid overview of ACT UP, beginning with the history of the gay rights movement and AIDS information. The current status of ACT UP is of a more passive nature. The weakest areas for the once extreme group are now the most important areas; media technology.

It is important to note the rapid decrease in public visibility of ACT UP. At the same time Larry Kramer was removed quietly from the group, each chapter apparently became run by its own members. The lack of leadership, or perhaps an overabundance of leadership, has caused great apathy and avoidance of the public attention the group once
thrived upon. While there is no direct way to map the removal of Kramer in correlation to the downward spiral of activity within the group, it is assumed that the timelines would be closely related.

The changes from ACT UP in the 1980s to today are drastic and obvious. The direct action which served as the backbone for the obnoxious and flamboyant group is now nonexistent. Instead, the Internet has become a poor substitute. The many leaders of the current chapters of ACT UP are apathetic, unwilling and not interested in promoting their cause. This is apparent in not only their webpages but also in their e-mail replies which consist of one sentence and usually direct all questions to the poorly-made webpages.

Bolter (1996) is correct when he claims that “cyberspace is a graphic space, and the role of prose, of discursive written communication, in cyberspace is problematic” (p.106). ACT UP chapters have made the mistake of assuming that the Internet is capable of reaching mass audiences. In fact, the audiences are available, but difficult to reach, especially by such poorly made and difficult to access webpages. Also, the total lack of direct action, replaced by Internet technology, has proven to be a nearly fatal wound to the group as a whole.

The primary goal of efforts by groups such as ACT UP is to pressure organizations into voluntarily correcting their behavior. However, government policy decisions may sometimes come into play as well. ACT UP has historically had problems with government, state, and local officials. The Internet can be a useful tool for changing the activist group’s standing in the overall organization. It can increase an activist group’s solidarity by allowing the activists to communicate across the network to other
activists or possible recruits. The Internet is a solid link for communication. While it is not a be-all, end-all source for information, it can be a very powerful tool. However, the legitimacy of the issue, the continual monitoring of the Internet (per server), and the limits of the Internet cannot be avoided.

Activists must frame an issue so that prospective members will find it legitimate and compelling. Without this legitimacy, activists are not effective and will not find a wider audience for their beliefs and concerns. Activists use their rhetorical skills to establish the legitimacy of an issue and to persuade others to accept their view of the issue (Heath and Nelson, 1984, p. 195). No communication channel is perfect for every target public and the Internet is no exception. The Internet is useless if the target audience (or prospective members) cannot or do not use it. Even if the target audience has access to the Internet, the activist must ask the questions “will they be able to find the website?” and “will they use the Internet?”

Activists must promote their websites and other Internet sources with as much effort as they approach their issue. Promoting a website involves being listed on major Internet search engines, such as Infoseek, Yahoo, or Dogpile, and urging similar web sites to provide a link to the activist group’s website.

Research is sorely needed in the areas of Internet effectiveness and use, especially for groups like ACT UP. The nature of activism has changed, and the presentation of values and beliefs has become easier in some ways and more difficult in others while changing from a human-based perspective (face-to-face interaction) to a technology-based perspective (Internet). While the media have always influenced the gay rights movement, the transmission of AIDS information, and the public attitudes and beliefs
towards social issues, the Internet is a huge new beast to be studied and tamed. ACT UP must rethink its efforts to reach any audience via new media technology. A group once so publicly visible has become lost in a huge cyberspace.
APPENDICES
ACT UP/Golden Gate
The San Francisco Chapter of the AIDS Coalition to Unleash Power

To contact us:
519 Castro Street #93
San Francisco CA 94114
Phone: (415)252-9200
Fax: (415)252-9277
e-mail: actup@actupgg.org

What's new at our site:

• Moderated e-mail list (LIPID LIST) to discuss metabolic complications being seen today in HIV disease:
  
  To subscribe send an e-mail to "listproc@critpath.org". The body of your message should contain"subscribe lipidlist firstname lastname"

Welcome! Please choose from the following options:

<table>
<thead>
<tr>
<th>About us</th>
<th>Abstracts &amp; Reports</th>
<th>Contact other ACT UPs</th>
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<tbody>
<tr>
<td>News Releases</td>
<td>Writer's Pool articles</td>
<td>Testimony</td>
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</table>

Trouble with Protease inhibitors?

We are collecting stories from people who have failed protease inhibitors, or who have had unusual responses to the drugs (e.g., no or delayed response). Please visit the Protease Inhibitor Response Project at http://www.pirp.org/
ACT UP/Golden Gate

The San Francisco Chapter of the AIDS Coalition to Unleash Power

Information about the AIDS Candlelight Memorial March taking place on Sunday May 16 is here.

To contact us
519 Castro Street #93
San Francisco CA 94114
Phone: (415)252-9200
Fax: (415)252-9277
e-mail: actup@actupgg.org

What's new at our site:

- Moderated e-mail list (LIPID LIST) to discuss metabolic complications being seen today in HIV disease:

  To subscribe send an e-mail to "listproc@critpath.org". The body of your message should contain "subscribe lipidlist firstname lastname"

Welcome! Please choose from the following options:

http://www.actupgg.org/
Contact Information

ACT UP Philadelphia
AIDS Coalition To Unleash Power

We meet every Monday night
at St. Luke's Church,
330 South 13th Street,
(13th St. between Pine and Spruce)
in Center City Philadelphia, at 6:00 p.m.

ACT UP Philadelphia
Post Office Box 22439 Wanamaker Station
Philadelphia, PA 19110-2439
E-Mail:

Telephone Number 215.731.1844
Fax Number 215.731.1845

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New York Golden Gate Paris

http://www.critpath.org/actup/ 1/13/00
ACT UP/New York

"Our Job is not to be invited to coffee or to schmooze at a cocktail party... Our Job is to make change happen as fast as possible and direct action works for that."

ACT UP is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis.

We advise and inform.

We demonstrate.

We are not silent.

some recent ACT UP links:

- Political Funeral
- NAMES REPORTING
- Clinton ZAPS
- Harm Reduction
- Youth AIDS Education Zine
- Research for Women
- After Ten Years...
- Paternalistic Academia
- Matthew Shepard

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- After Ten Years...
- Matthew Shepard
- Immigration bill....

http://www.actupny.org/
Hey kids, it's open season on people with AIDS! Grab your bats and be just like your fog-bashing heroes! Collect the entire set of 1995 "World Series of AIDS Bigotry" Trading Cards featuring all of your Republican favorites in action. Experience the excitement of oppressing gays and lesbians. Feel the thrill of driving an HIV-infected community into an early grave. And remember, with the '96 elections just around the corner it's time to...

GET 'EM ALL!
MURDERER, LIAR
& DRUG CO. PIMP
BIBLIOGRAPHY

Available: http://www.actupgg.org

http://www.actupny.org/

http://www.critpath.org.actup

actupsf@aol.com

Interplay: The process of interpersonal communication. New York: 
Harcourt Brace College Publishers.

organizational transformation of advocacy: Growth and development of AIDS 
community-based organizations. AIDS & Public Policy Journal, 10(1), 48-60.


Barge, J.K. (1989). Leadership as medium: A leaderless group discussion 


Grasen, E. (1996). Thinking critically about world wide web resources. estherg@library.ucla.edu.


Kramer, L. (1992). We have lost the war against AIDS. *USA Today*, 120(2564), 72-75.


Public Media Center (1996). The impact of homophobia and other social biases on AIDS. *A Special Report by Public Media Center*, 1-34.


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