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INFORMED SURVIVAL:

MEDIA ACTIVISM BY PEOPLE WITH HIV/AIDS

By

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MEDIA ACTIVISM BY PEOPLE WITH HIV/AIDS

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ABSTRACT

This study looks at print media projects by and for people with HIV/AIDS. Three types of publications are examined: newsletters; treatment publications; and general interest magazines. Each of these media began as part of political organizing by people with HIV in the context of the community-based response to the AIDS epidemic. The argument is made that those involved in contemporary social movements produce their own media as a means of constructing an alternative public sphere. The significance and function of this public realm is twofold. First, it is a social space for people with HIV/AIDS that is independent of forms of institutional influence and control. Second, it invites not only the articulation of opposition to the dominant social order but an alternative to the status quo. This study demonstrates the role of communication media - forums through which people can share their experiences and knowledge - in the struggle for self representation and survival among people with HIV/AIDS.

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TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION

'Informed Survival' is a slogan used by Community Prescription Service, a company that orders and delivers medications and supplements for people living with HIV/AIDS. Interestingly Community Prescription Service provides a selection of treatment publications with each prescription. It is even possible to send copies to your primary care physician, if desired. The rationale for this additional service is that people with HIV/AIDS need to be able to make informed decisions about their health care in order to survive, and that treatment publications are an important and reliable source of information about managing HIV infection. According to the founders of the company, all of whom are HIV positive, it is not enough to simply receive medications; people need to have information that will help them develop an approach to living with HIV/AIDS.

Currently in North America, treatment publications are only one resource among many that are available to people who wish to learn more about managing their HIV infection. In fact, there is an abundance of information: guides to health management, books on spiritual growth, advice on legal issues, manuals on safer sex, pamphlets on the latest treatment protocols, and so on. In many cases, much of this information is published by government agencies, health professionals, pharmaceutical companies and even academics. However, an interest in the needs and concerns of those HIV infected by social institutions like the state, medicine, and corporations is a recent development. Instead, over the past fifteen years people

with HIV/AIDS have informed each other in many cases through the programs and services

offered by community-based organizations. Sears (1991: 43) has described this organizing as

> a diverse set of responses counterpoised from the onset to that of public health and
> other state agencies... .These organizations range from relatively large staffed
> agencies following a conventional social service model, to People With AIDS groups
> based on philosophies of self help, to activist groups committed to mobilization for
> social change ... .

The development of media projects has been a key component of this community-based

response to the AIDS epidemic. Publications, telephone hotlines, posters, fax, video,

television, radio, and more recently the internet have been utilized as a means of outreach and

community development. Alternative forms of communication were necessary given the lack

of an institutional response to HIV/AIDS. The publications offered by the Community

Prescription Service - *AIDS Treatment News, Beta, POZ, Notes from the Underground,*

*Treatment Update*s - are examples of print media that have been created and sustained

through the AIDS movement. Rather than relying on social institutions, such media practices

among people with HIV/AIDS have sought to exert control over the meaning of HIV/AIDS.

While there are some indications that social institutions appear to be more responsive in

managing the AIDS epidemic it still remains unclear as to whether the lives of those infected

are considered to be a priority. It is in this sense that media by and for people with HIV/AIDS

(also referred to as PWA media) can be thought of as a form of activism. [1]

In this study I examine a selection of print media projects as examples of activism by

people with HIV/AIDS. The introduction to this research is divided into four parts. The first

traces the origins of the project and discusses the reasons why I chose to study PWA media.

The second provides an overview of PWA media projects with specific reference to those

publications included in this study. The third section outlines the approach that I have taken to the study of media activism by people with HIV/AIDS. And, the last section is a brief guide to reading this study.

The Origins of this Project

In 1994 I was hired as a research assistant for a project on the role of people with HIV in the Canadian AIDS movement. [2] This work involved reviewing the literature on organizing among people with HIV/AIDS in North America. After much searching and frustration, I realized that while there was literature on the community based response to HIV/AIDS, the contributions of people with HIV/AIDS had not been examined in any depth (Altman, 1986; Patten, 1985; 1990; Cain, 1993a). In fact, it was difficult to find any background information on organizing by and for people with HIV/AIDS (also referred to as the PWA self empowerment movement, or simply the PWA movement). The librarian at the AIDS Committee of Toronto suggested that I look at the periodicals in their resource centre. Here I found a wealth of information about the PWA movement in publications like *Newslines, Body Positive, Beta,* and *Positive Living.* Moreover, I was fascinated to learn that people with HIV/AIDS, through their involvement in the AIDS movement, had created their own publications as a means of self empowerment and self representation. As I read through these publications, it occurred to me that looking at the alternative media projects that have been developed by and for people with HIV/AIDS would make an interesting research project.

The rationale for this study was not based on personal interest alone. I was also aware that a study of PWA media would be relevant to several substantive areas in the literature on HIV/AIDS in the social sciences. For instance, in terms of research on the community-based response to HIV/AIDS, examining PWA media would be a way of further understanding the PWA movement. Also, I was aware that research on HIV/AIDS and the media had focused on mass communication (Buxton, 1991; Nelkin, 1991). A study of publications by and for people with HIV/AIDS would be an opportunity to focus on alternative media practices. And lastly, it had become evident from my reading that there were few studies of people living with HIV/AIDS. I thought a study about PWA media would be an opportunity to look at the way in which the experience of HIV/AIDS had been represented by those living with the disease. Part of the appeal of this project was that it provided an occasion to address questions in the existing literature in sociology and the social sciences generally (AIDS organizing, HIV/AIDS and the media, and the experiences of people with HIV/AIDS) that had not yet been examined. It also reflected a shift in my own thinking about sociology. Instead of focusing on aspects of the dominant social order, I wanted to develop a study that examined the critical practices of marginalized or oppressed groups.

In 1995, I began to develop a plan of study for this project. I started by tracking down and reading the back issues of four media projects that I thought would be good candidates for the study. I subscribed to each of these publications and started to read all of the current issues. After this background work, I began contacting people for interviews and for more detailed information. At this time, I had the opportunity to became involved in the production of two local treatment publications. They fit well into the framework that had emerged for

the project so they were added to the study. Over the past three years I have become immersed in various aspects of these six media projects. My reading of these publications, and my contact with those involved in their production, has served as the basis for this study.

An Overview of PWA Print Media

The development of PWA print media has been a key component of organizing by and for people with HIV/AIDS over the past fifteen years. The prevalence of such projects is understandable given the emphasis that has been placed on staying informed as essential to survival within the PWA movement. Generally speaking, publications by and for people with HIV/AIDS tend to fall into three categories: newsletters, treatment publications, and general interest magazines. It is interesting to note that each type of PWA media emerged at a distinct period in the PWA movement. Generally speaking, newsletters were the first type of media project, emerging during the early period of the PWA movement. They were followed by treatment publications which became most prevalent four or five years into the history of organizing by and for people with HIV/AIDS. And lastly, general interest magazines have become more prevalent in the last five years, the most recent period of the PWA movement. The argument could be made that during each period of the PWA movement a different type of media project predominated: newsletters during the early period, treatment publications during the middle period, and general interest magazines during the most recent period. In terms of this project, I felt it was important to include examples of PWA media from each of these three categories; hence, there are two newsletters, two treatment publications, and two general interest magazines. [3]

Newsletters

In the 1980s, when people with HIV/AIDS began to form their own organizations, they also started agency newsletters. As the PWA movement has expanded, it is a common practice for new organizations to produce their own publications. As a result, newsletters are arguably the largest category of PWA media. Generally, such media are used in two ways. First, they provide information about their parent organization. And second, they are a form of support and education for people with HIV/AIDS and are often built into the programs and services offered by organizations.

BCPWA News is the oldest of the two newsletters in this study. It is a publication of the British Columbia Persons with AIDS Society, a Vancouver based organization that formed in 1985. The newsletter follows the mandate of the organization which is to "empower persons living with HIV disease and AIDS through mutual support and collective action." *Body Positive*, the second newsletter, is produced by an organization of the same name. Body Positive began in New York in 1987 to assist people when they first acknowledge the impact of HIV/AIDS in their lives. For instance, Body Positive is oriented toward people who have been newly diagnosed with HIV or AIDS. Like the programs offered by the organization, *Body Positive* is based on a "peer model of self help that offers information and support to help make decisions that can increase life expectancy and quality of life." This chapter examines how newsletters have evolved in relation to changes in the PWA self empowerment movement.

Treatment Publications

In the 1980s there were a sparse number of grassroots AIDS treatment publications. Into the 1990s treatment media projects began to flourish on a much broader scale. The two treatment publications in this study are *The Positive Side* and the *Treatment Information Flash*. Each were started as part of this general trend toward the development of print media dedicated exclusively to the provision of information about health and health care.

The Positive Side was started in 1991 in Toronto. It was the product of a collective made up of people with HIV/AIDS. The intent was to create a forum for health information and viewpoints that placed emphasis on the different approaches that people with HIV/AIDS were using to manage their health. The group wanted to popularize information about treatments and reach as wide an audience as possible. To meet this end, the collective worked in association with, and later as a part of, a Toronto based organization called the Community AIDS Treatment Information Exchange (CATIE).

Early treatment media provided a basis for subsequent projects, as in the case of the *Treatment Information Flash*, the second treatment publication included in this study. The objective of this project was,

> to provide treatment information that is current, accessible and relevant to the needs of people with HIV/AIDS in our area. We intend to involve a diversity of people in the HIV/AIDS community, including people with HIV/AIDS, caregivers, doctors, nurses, and complementary therapists.

The *Treatment Information Flash* was initiated in 1996 by a group of people infected by HIV/AIDS and volunteers as part of the peer support program at the Hamilton AIDS Network.

Unlike agency newsletters, many AIDS treatment publications, including the two in this study, have not survived. The chapter on treatment publications focuses on two issues. First, it examines the rise of such projects, driven by collectives of people with HIV/AIDS. And second, it looks at their subsequent decline, as print media have been replaced by electronic media and treatment counsellors as the preferred approach to providing health care information to people with HIV/AIDS.

General Interest Publications

In the 1990s a new type of PWA media emerged, in part because people with HIV/AIDS with an interest in writing and in journalism began to produce their own publications. I have referred to this type of publishing collectively as general interest magazines, but in fact there are two types of media included in this category. For instance, those involved in the first general interest magazine *Diseased Pariah News (DPN)* consider the publication to be a 'zine' not a magazine. Zines are independently produced (self funded) publications, usually through desk top publishing, that are like a magazine in spirit, only smaller, rougher, and often satirical, personal, and political in content, tone and style. *Diseased Pariah News* was started in 1990 in San Francisco by a group of gay men with HIV/AIDS. According to the founders, *DPN* is

> a patently offensive publication of, by, and for people with HIV disease (and their friends and loved ones). We are a forum for infected people to share their thoughts, feelings, art, writing, and brownie recipes in an atmosphere free of teddy bears, magic rocks, and seronegative guilt.

In addition to zines, there are also several HIV/AIDS specific publications that are much more akin to mainstream glossy magazines in appearance, content, style, and tone. *POZ*, the second general interest magazine in this study, has been at the forefront of such media projects. This magazine is supported primarily through subscriptions and advertisements from AIDS industries like pharmaceutical companies. In terms of its main objective, according to the magazine's founder Sean Strubb, *POZ* "sprang out of my desire to simplify, popularize and broadly disseminate the huge volume of life-sustaining information - and inspiration - I had already found critical to my own survival."

Distinct from prior PWA Media, publications like *POZ* and *DPN* tend to be more autonomous. They are not formally linked to or supported by PWA organizations and they are directly committed to being a forum for the writings, opinions, and profiles of those HIV infected and affected. The chapter on general interest magazines examines how *POZ* and *DPN* have represented what it means to be a person with HIV/AIDS from the perspective of the PWA movement.

PWA Media as a Genre

The distinction between newsletters, treatment publications, and general interest magazines provides a framework for the structure of my analysis. Nonetheless, having looked at countless publications in Canada and the United States, it is evident that, even though there are differences, all share certain qualities that make them part of the same genre. First, they are informed by the political ideologies that have provided the foundation for the PWA movement. A central feature of this ideology is that those infected and directly affected by

HIV/AIDS need to be directly involved in and have control over the decisions that affect their lives. Second, media by and for people with HIV/AIDS are also supported, directly or indirectly, by the organized HIV/AIDS community. Third, the content of PWA media - text and images - is conveyed from the perspective of those infected with HIV/AIDS. In most cases this perspective is the direct expression of people living with HIV/AIDS. And fourth, there is an emphasis in PWA media on conveying or sharing useful information or practical knowledge about surviving and living with HIV/AIDS.

The PWA movement has had a significant impact on addressing the needs and interests of people with HIV/AIDS through strategies of self help and self empowerment. By organizing, people with HIV/AIDS have developed needed programs and services and transformed the meaning of HIV/AIDS. Among the advances made by people with HIV/AIDS, one of the most distinctive aspects of the PWA movement has been the development of this genre of print media projects. More than in other social movements in health, people with HIV/AIDS have taken advantage of alternative media as a form of self representation and self empowerment.

My Approach to the Study of PWA Media

In examining PWA media - as a genre - my approach has been to treat them as part of efforts among those involved in new social movements to construct an alternative public sphere (Fraser, 1992). As Marshall (1991) has argued, contemporary social movements - feminism, environmentalism, gay liberation - have each created alternative public spheres through the use and development of communication media like print media, hotlines, videos,

film, radio, and so on. Such alternative media function as a public forum on two levels. First, they provide a means for people to share and articulate a critique of existing forms of domination. And, second, they provide a means for people to share their experiences and construct collective identities. It is in this dual sense that social movement media can be considered counter-hegemonic: in creating a public sphere they provide an alternative perspective to ideas and meanings legitimated and reproduced through the dominant social order.

In the case of the PWA movement, the construction of an alternative public sphere has focused primarily on fostering collective identities among people with HIV/AIDS. Objectives like educating the general public or influencing public policy have generally been secondary, though clearly addressed in terms of encouraging those infected to become politically involved. The formation of community-based PWA organizations has been at the centre of such efforts. As Altman (1994:62) has noted,

> PWA organizations function as much as self-help groups as they do as advocacy organizations, and for many their most important role is indeed the creation of a space where people with AIDS can share experiences and find the comfort of not having to explain the realities of their situation because it is taken for granted.

The forums and social spaces that have emerged through PWA organizing, of which print media have been an important part, have provided the means by which those infected can foster and construct collective identities based on a positive and empowered concept of what it means to be a person with HIV/AIDS. In many respects, this process of identity formation is considered to be essential to the provision of education, support, and advocacy by and for people with HIV/AIDS (Rank et al, 1992; Ariss, 1993).

This understanding of the connection between alternative media and social movements raises several questions in terms of the publications included in this study:

1. How have print media - as a public forum - changed in response to changes in the PWA self empowerment movement and changes in the AIDS epidemic?

2. How are PWA print media distinctive as an expression of those with HIV writing for the benefit of the HIV/AIDS community?

3. How do PWA media represent what it means to be a person with HIV/AIDS, or in other words, how do they construct PWA collective identities?

In my analysis of newsletters, treatment publications, and general interest magazines I address these questions in an attempt to understand how PWA media projects have contributed to the construction of an alternative public sphere for people with HIV/AIDS.

A Brief Guide to Reading this Study

Organizationally, this study is divided into two parts. The first part consists of three chapters that outline the academic context for researching PWA media: relevant literature in the social sciences; methods and methodology; and the overarching theoretical framework. The second part consists three chapters that address substantive issues and questions regarding PWA media. Each substantive chapter explores a specific question in regard to a particular type of PWA media. The first chapter examines PWA newsletters - specifically, the social forces that have contributed to their evolution and development. In the second substantive chapter, I look at the role of small scale treatment publications in providing "community-based" information about health and health care is produced and disseminated.

The chapter on general interest magazines examines the way in which HIV/AIDS has been represented in magazines produced by and for people with HIV/AIDS. In the conclusion I explore the connections between the PWA movement and social movements in health in terms of the potential of media projects in the construction of alternative public spheres.

Dividing the substantive chapters up into three discrete case studies involving different types of PWA media was necessary to manage the breadth of data resulting from field work, interviews, and texts from current and back issues of the six publications. Moreover, in many ways the analysis grew from common themes within types of media. For instance, it made sense to focus on the history of newsletters because they have been the most enduring type of PWA media. Similarly, general interest magazines have devoted the greatest attention to struggles over the meaning of HIV/AIDS by highlighting the experiences and reflections of those infected. As a result, the content lent itself to an analysis of how PWA media have constructed PWA collective identities. However, the analysis conveyed in each chapter was not completed in isolation. Data collected from all six publications was used to inform the analysis of each specific type of PWA media. To bring the study to a close, I expand on the idea that, despite the divisions in terms of type, print media by and for people with HIV/AIDS are still inter-related as part of a struggle for self representation.

FOOTNOTES

1. 'PWA' refers to persons with AIDS. It refers usually to a project or organization or movement by and for people with HIV/AIDS. Since not all people with HIV are diagnosed with AIDS the use of PWA to refer to individuals has become less common and less favourable, although it is still dominant. Instead, several different acronyms are currently used to refer to people with HIV or AIDS: PHA (people with HIV or AIDS); HIVers (persons with HIV but not AIDS); PWARC (persons with AIDS Related Complex, a term used prior to the test for HIV infection); PLWHA (people living with HIV or AIDS). In this study I use the term PWA in reference to organizations and media projects. I have tried to avoid using acronyms for people with HIV/AIDS.

2. This project was eventually published as a book, entitled *Living and Serving: The Role of People with HIV in the Canadian AIDS Movement* (Roy, 1995).

3. The rationale that I used for selecting the publications in this study is discussed in more detail in the methodology chapter.

CHAPTER TWO: METHODOLOGY

In the social sciences there is a growing trend toward developing methodologies that foster a closer alliance between academics and those groups, communities, or individuals who are the subjects of social research. This shift to a more community-oriented approach has been promoted in many different forms: action research, activist research, participatory research, and most recently, participatory action research (Whyte, 1991). The common elements among these methodologies, according to Petras & Porpora (1993:108), are:

> (1) a commitment to the needs and interests of the community; (2) a direct engagement with the community so as to permit its problems and goals to be defined in its own voice; and (3) a moral commitment to the transformation of social, political, and economic injustices directly affecting the community studied.

This general approach to research, which I will refer to as participatory action research (PAR), has emerged from several sources: community projects in developing nations, research with intercity communities, and feminist methodologies. There are similarities between PAR and early forms of qualitative research emphasizing participant observation and an identification with the powerless or the underdog (Becker, 1967; Denzin, 1992). What distinguishes PAR is the degree to which groups or communities have direct control over the research process, and the emphasis on integrating initiatives for social change into the research agenda.

The extent to which these objectives are upheld varies according to whether academic or community issues are emphasized in the research. In the area of HIV/AIDS, Smith's activist

ethnography of the group AIDS ACTION NOW! is an example of a more 'pure' form of participatory action research (Smith, 1990). With pressures on academics from universities and funding agencies, this more activist form of PAR tends to be the exception rather than the rule. When Cancian (1993) interviewed academics who subscribe to PAR, she found that they developed strategies allowing them to retain control over the research process, and they negotiated a compromise between their interests as academics and the interests of the communities they studied. For instance, the implementation of 'action' initiatives depended on the availability of resources and the pressure placed on them to publish.

In developing an approach to this study, I was drawn to the ideals of PAR. I realized quickly, though, that this was unrealistic given my status as a graduate student and my relationship to the community-based AIDS movement. After reading an article in *Body Positive* in which stated, "AIDS activists need allies ... among scientists, the press, and in government in order to prevail," it occurred to me that the idea of allied social research might provide a compromise between PAR and the objectivism of conventional sociology. In this chapter I clarify what I mean by allied research and outline why I felt it was necessary. I also outline the methodological framework that was used. And lastly, I describe the research process involved in conducting this study.

Allied Research

Why was participation action research not an option for this study? First, it is an approach that is not particularly suited to conducting research as a graduate student. Using a methodology grounded in the principles of PAR has benefits and drawbacks for graduate

students. This approach provides valuable insight into the politics of academic research and the need for greater accountability and commitment within the social sciences to the world beyond the university. At the same time, though, PAR can create unrealistic expectations if graduate students place more emphasis on making their research useful and applied rather than on fulfilling the objectives of their program of study. In conducting this research I have learnt that, in a field like sociology, a PhD dissertation should be primarily an academic exercise, designed to develop research skills and to demonstrate competency within a specific social scientific discipline. I am not saying that graduate students cannot or should not conduct PAR. However, they need to be fully aware of the time and commitment that is required and that this approach to research is viewed as marginal and unorthodox, even inappropriate, within many academic circles.

A second barrier to making use of PAR was my own ambivalent relationship to those communities directly affected by HIV/AIDS. As an HIV negative, heterosexual man with very little involvement in the community-based AIDS movement, I had not yet established and did not feel comfortable with my own position in relation to AIDS organizing or those communities directly affected by HIV/AIDS. On an academic level I knew that it was impossible for me to study PWA media and not be a part of the AIDS movement. By selecting the social aspects of AIDS as a topic to study I was by implication involved in the AIDS movement. Weber made this fact of social research clear in his idea of a value free sociology (Weber, 1949). According to Weber, sociologists should exercise their values in selecting a topic to study, but, once the topic is selected, they need to remain as objective as possible. In contemporary sociology, more scholars are recognizing that it is not possible to

provide an account of the social world that is free from subjective interpretation, as Weber had envisioned (Belsey, 1980). My perspective on this issue follows that of Bourdieu (1996), who argues that rather than creating a cloak of objectivity, the sociologist should try to be aware of his or her perspective and make this point of view explicit when conducting and writing social research. The decision to conduct this research was at the same time a decision to become more involved in the community-based response to HIV/AIDS, and a decision to become more involved in print media by and for people living with HIV/AIDS.

The question, then, was not whether I would be involved personally but figuring out how and at what level I was going to be involved in PWA media projects and AIDS organizing generally. The challenge was to develop an approach that allowed me to articulate a point of view that I felt comfortable with - a point of view that would allow me to participate in a community-based movement on a personal level and as a researcher when I was not in fact a person infected or affected by HIV/AIDS. As well, I needed an approach that would allow me to produce a research project that would allow me to progress toward completing my degree, and that would be relevant to the needs and interests of people with HIV/AIDS and the community-based AIDS movement.

As is often the case, I came upon an adequate approach gradually as the project developed. When I first became involved in research on the social aspects of HIV/AIDS, the subject matter felt abstract and removed from my everyday life. Most of what I knew about HIV and AIDS came from the mass media and my readings as an undergraduate. For instance, when I first became involved in AIDS research as a graduate student, my only introduction to identity politics and the AIDS movement came from reading "Is the Rectum

a Grave?" by Bersani (1988) as part of an undergraduate contemporary theory course. This article illustrated to me for the first time how institutional discourses about HIV/AIDS were being created not in order to guide a constructive response to a potentially devastating health crisis, but instead, to police, repress, and oppress forms of sexuality in general and gay sexual liberation in particular. I found this argument compelling; it seemed to me to provide a critical insight into the politics surrounding HIV/AIDS. At the same time, though, topics that the article dealt with - gay sexuality and HIV infection - felt abstract and foreign. Having the opportunity as a graduate student to participate in research on AIDS organizing brought me closer to the social world of HIV/AIDS and to the people and the issues that I had only read about previously in articles and books.

By the time I began this project, my relationship with the AIDS movement, though still ambivalent, had developed. My participation in research about AIDS continued and I was fortunate to become involved in projects on the use of alternative therapies by gay men with HIV/AIDS and on the role of people with HIV/AIDS in the AIDS movement. Through this research I was introduced to many people infected and directly affected by HIV/AIDS who had a strong commitment to the AIDS movement. Greater proximity to those connected with AIDS organizing helped me to foster a greater personal identification with the efforts directed at providing education, support and advocacy for people with HIV/AIDS. Eventually, this contact was one of the main reasons why I chose to look at the communication and self representation strategies used by groups of people with HIV/AIDS.

In developing an approach to this study my initial ambivalence and distance from the lived experience of HIV/AIDS made it difficult to imagine entering into a research project about

media projects by and for people with HIV/AIDS that subscribed to the ideals of PAR. I simply was not prepared, nor did I have the background, to be an activist ethnographer. At the same time, I wanted this research to at least remain consistent with the broad objectives of PAR. For instance, I felt that research on HIV/AIDS had not adequately looked at topics regarding the needs and interests of people with HIV/AIDS. Additionally, it was important to me that I engage directly with those involved in media projects in order to understand their perspective. However, for practical reasons mostly, I was less interested in sharing control of the project, though I was open to direction and guidance from those in the project. Similarly, I was wary of building "action" initiatives into the study as part of a moral commitment to transforming injustices affecting people with HIV/AIDS, though, I tried to look at topics that might be useful to those who are involved in community-based media projects (like the factors that have contributed to the success and failure of media projects in the study). In weighing these factors, I decided to orient the study toward academic versus community issues (after all it is an academic dissertation, written by a sociologist for sociologists) but tried as much as possible to understand, become involved in and be sensitive to the struggles of people with HIV/AIDS to represent themselves through the development of media projects.

It is in this sense that I think of my approach as being allied with the community-based AIDS movement. It has directly informed how I have conducted this study. Initially, when the research began, I entered the field by reading every back issue of every AIDS publication that I could find. This required that I spend much of my time at the resource centre at the AIDS Committee of Toronto. At this early stage, I perceived myself as a familiar nuisance, digging

through the vertical file of periodicals and monopolizing the photocopier whenever it was not being used. At approximately the same time I decided to start volunteering at the Hamilton AIDS Network (HAN), initially with their resource centre, then later with the publications they produce, and then as a member of their Board of Directors. Soon after this, I also started volunteering at the Community AIDS Treatment Information Exchange (CATIE). At this stage of the research I tried to balance my interests as a researcher and a volunteer. I explained that my volunteering was part of developing a project on AIDS publications and because I was interested in getting more personally involved at the community level.

As I became more involved in volunteering with local publications I started to contact those involved in different print media to see if they would be interested in participating. When I spoke to the staff of publications in Vancouver, New York, and San Francisco I presented the research both as my PhD dissertation and as a project that would be beneficial to the publications that I was involved in at HAN and CATIE. I believe that if I had approached the publications in other cities without some affiliation to local AIDS groups, they would have been less open and accommodating. At the same time, I was concerned about not being perceived as an opportunist who is taking advantage of and perhaps misrepresenting the efforts of people with HIV/AIDS and community-based AIDS organizing. Demonstrating my involvement in AIDS work at the community level was a means of justifying the study to respondents and to myself.

As the research developed so did my personal involvement in volunteering. While I did feel a closer identification with the AIDS movement, nothing reminded me more of my marginal position than those situations that required disclosure. I felt awkward volunteering

as a person who is not a member of those communities directly affected by HIV/AIDS - I felt consistently like a guest visiting the AIDS movement, mostly welcomed but occasionally unwelcomed. In addition, as a white middle class straight man, I am part of a privileged class in North America that has been particularly hostile toward issues of gay liberation, women's rights, and PWA self empowerment. The difficulty of disclosure was the several layers of fear that it engendered: I did not want to be viewed as the oppressor; I did not want to be rejected; and I did not want to create distrust and distance between myself and those people that I was working with and those who were respondents in this study.

Disclosure also raised the issue of acceptance and legitimacy in the research setting - if I was perceived as too much of an outsider, then that forced me to question what right I had to conduct this research. By volunteering, my acceptance felt like an endorsement for my research as well. It was important that I remain marginal - too much involvement met with suspicion while not enough meant that I was not serious about the research. There were times when I did not disclose my sexuality when I probably should have because the situation felt too uncomfortable. Occasionally, my identity was questioned and challenged by those people I was working with or interviewing - I had to disclose and justify my involvement whether I wanted to or not. There were other times when I challenged myself - when it would have been easier to pretend that my sexuality or my HIV status was not an issue - and disclosed because I knew it was indeed an issue. Disclosure was an ongoing challenge for me in this research. As my comfort level increased, so did people's trust that my involvement was as an ally; they believed that I did not have an ulterior motive in conducting this research.

While conducting this research I felt more comfortable about my involvement in the community-based response to HIV/AIDS. I tried to be aware of the interests and concerns of people living with HIV/AIDS. I also tried to support and endorse struggles toward liberation and self empowerment and efforts to challenge social inequalities and forms of oppression. For instance, while completing this project there are times when I write about people with HIV/AIDS, but I have tried to resist speaking for those infected. Instead, I have tried to highlight ways in which people with HIV/AIDS have tried to speak for themselves and for each other.

The struggle for representation is common in social situations dominated by identity politics. And, it raised an interesting methodological issue as the research progressed. Initially, I began the research as an outsider based on my identity and my proximity to AIDS organizing. However, as my proximity and involvement in AIDS organizing increased I became, on one level, more of an insider - I was directly aware of the issues and problems faced by people with HIV/AIDS in AIDS organizing. At the same time, I still considered myself as an outsider. The position that I occupied as a researcher was paradoxical; I was both inside and outside of the situation that I was studying. As in any research, this perspective had its advantages and disadvantages. For instance, as an outsider, learning to feel comfortable writing about people with HIV/AIDS was difficult and took at long time especially given that I was looking at how those infected have struggled to create the means to write about themselves rather than having people write about them. As the same time, accepting that at another level I was also an insider gave me the permission to learn to write about the ways in which people with HIV/AIDS have created their own means of

representation. I like to think that this continued ambivalent position as a researcher in relation to AIDS organizing has helped me to provide insights into media activism among people with HIV/AIDS.

Methodological Framework

Turning to the methodological framework used in this research, the strategies used to collect, code, and analyse the data for this research are drawn from both cultural studies and grounded theory. In cultural studies, several models of cultural circulation have been proposed in order to better understand the production and consumption of cultural commodities within late industrial capitalism (Hall, 1980). The model developed by Johnson (1986/7) provides the most useful conceptual framework for this research. This 'circuit of culture' model divides all forms of cultural production into four interrelated historical moments: (1) production, (2) texts, (3) readership, and (4) lived cultures. It was designed, in part, as a means of providing some structure to the emerging field of cultural studies. Each historical moment also refers to an area of research within cultural studies. For instance, historically work in cultural studies has focused on cultural texts or the political economy of cultural production (the first and second moment). Recently, there has been a trend toward examining how texts are read by audiences, and the impact of this reading on local lived cultures (the second and third moment). Johnson, in creating this model, has tried to foster a field of research that examines, at some level, all aspects of cultural production and consumption - particulariy in light of how they are linked.

For the purposes of this research, I began using this 'circuit of culture' as way of conceptualizing the production, distribution and consumption of print media by and for people living with HIV/AIDS. The difficulty that I found was in considering all moments in a single study. As a result, I began to use this model by taking the perspective of those producing these print media and I used the four moments as the basis for the development of research questions in which to guide the collection, coding and analysis of data. Taking this approach led to four main questions: (1) how are PWA media produced? (2) what is represented in PWA media? (3) who is the intended audience for PWA media and how are they reached? (4) what assumptions are made about how people use PWA media? I soon realized that this approach was too broad. It would be difficult to address the last two questions given that I was primarily looking at interviews with producers and the content of the publications. As a result, early in the process of collecting and analysing the data, I decided to focus more specifically on questions regarding the production and the content of the print media and the relationship between the print media and the community-based AIDS movement. I still asked questions regarding the intended audience and use by readers but only in terms of how producers understood and addressed these issues in their work.

With this more practical and concrete focus in mind, I turned to grounded theory as a means of collecting the data around each issue or question. Using a pre-established framework precluded the option of using grounded theory in its 'pure' form (Glaser and Strauss, 1967). If I were to use grounded theory in this way, my focus would have come from the data in an emergent and naturalistic manner. As Schatzman and Strauss (1973: 7) explain, "in a grounded theory approach to research, theory and method continually inform each other

on the basis of "strategic decisions, instrumental actions and analytical processes...which go on throughout the entire research enterprise."

There are theoretical assumptions built into the cultural studies framework that I have chosen for this research. The structure of the research, and the data collection, coding, and analysis, are already driven by assumptions about the process involved in cultural production and consumption. This approach does not however preclude the use of grounded theory. I have used a grounded theory approach within each of the four moments in Johnson's circuit of culture. For instance, in exploring the question of how AIDS publications are produced, I did not impose prior notions of what I expected was the case on the research setting. Instead, I allowed themes to emerge from of the various forms of data that I had collected. Instead of entering into the field and developing a focus for the project based on the issues and questions as they emerged from the data, I used Johnson's model as a pre-set framework for my data collection. As the research process evolved I tried to work within this framework but also to adapt it in relation to the data that I was collecting. [1]

Research Process

The research process itself occurred in three phases. In the first phase I concentrated on collecting data from the publications, from field work, and from interviews. The second phase involved reviewing, coding, and analysing the information that I had collected. The final phase focused on formulating and writing my analysis of PWA media projects. As is apparent in my discussion of each phase, there was not a direct linear progression from data collection, to

analysis, to writing; instead, the research process moved back and forth between phases slowly moving closer to a completed written analysis.

At the beginning of the project my focus was on collecting data. I started by collecting and reading back issues of the publications. In some cases, they were made available by the organizations for a minimal charge. If back issues were not available I relied on the archives of local AIDS organizations. Fortunately, the AIDS Committee of Toronto resource centre had a complete archive of most of the publications in the study. Issues missing from their collection were found by accessing the archive at the Community AIDS Treatment Information Exchange. [2] One of the interesting qualities of archives like the one at the AIDS Committee of Toronto resource centre is that they are ever changing - issues disappear, but as soon as they are gone, another set of back issues magically re-appear because someone has donated their collection of publications. For instance, for many of the early issues of the *BCPWA News* were missing - then they appeared one week, giving me time to photocopy them, and the next month they were gone again. Another obstacle was the inconsistency in publishing issues. Often publications that claimed to be produced bimonthly actually were only able to produce three of four issues a year. It was difficult to investigate whether the missing issues were not available or whether they existed at all. [3]

At this time I also subscribed to all the publications in order to receive new issues. In fact, I have continued my subscriptions throughout the research process. Instead of identifying a clear date at which to stop analysing the publications I have continued to look at new issues as they arrive. For practical reasons, I stopped coding and analysing each issue in depth once

I began the writing process. However, I still look through new issues as they arrive to keep in touch with the publications and the questions they raise.

Once I had started the process of reading back issues, I began to volunteer for the *Treatment Information Flash* and the Hamilton AIDS Network and for *The Positive Side* at the Community Treatment Information Exchange (CATIE). Becoming involved locally in AIDS organizations in Hamilton and Toronto provided opportunities for me to experience first hand what is involved in producing print media by and for people living with HIV/AIDS. Unfortunately, neither of these publications are currently being produced.

At the Network I wrote and researched articles for the publications on topics such as mental health and HIV and the role of pets as a form of social support. I worked with a group of volunteers under the supervision of a staff member responsible for the peer support department of the agency. This publication was designed to provide more services around treatment and support to people with HIV/AIDS. It was also intended to encourage greater involvement by people with HIV/AIDS in the organization.

At CATIE, I asked to become involved in a small collective of volunteers who produced *The Positive Side*. This publication provided general health information, but mostly information about alternative health care. Although most people in the collective are HIV positive the group is open to those people interested in holistic health and HIV/AIDS. As part of this group, I was involved in monthly editorial meetings, writing and researching articles, and endeavouring to ensure that the publication survived.

This involvement in the field provided insights into community-based publishing that I would not have gained through interviews or through reading back issues. While it was not

possible for me to become involved in all of the publications, being involved in two projects, in addition to reading all of the back issues, enabled me to develop a more precise interview guide in which to base the interviews with people involved in the other four publications.

After several months of field research I began contacting those involved in the other publications and arranging interviews. The interview guide that I developed was loosely structured around the six main areas. First, I asked respondents to talk about their history with the publication and their understanding of the publication's historical development. Second, I asked a series of questions regarding the relationship between the publications and the AIDS movement (connections to AIDS organizing, the PWA movement, the organized gay community). The third set of questions related to the overall purpose or objective of the publication. Fourth, respondents were asked to describe how the publication is produced on an issue to issue basis and how this production has changed over time. In relation to production, questions were also asked about the role of people with HIV/AIDS and how the production process was funded. The fifth series of questions related to the content of the publication. Respondents were asked about the rationale for the information in each issue and the role of the editors in this process, how people with HIV/AIDS are portrayed, and whether there is a particular emphasis placed on AIDS prevention, education, or support. Lastly, respondents were asked questions about how the publication is distributed, who the intended readers are, and what impact they thought the publication had among readers.

Most of the interviews with local people were conducted face to face and lasted approximately 45 to 90 minutes. The interviews with those involved in the publications in Vancouver and New York were conducted over the phone. I faxed the interview information

to these respondents prior to the interview so that they would be prepared for the issues and questions addressed in the interview. This strategy tended to work very well. It is possible that using the phone created barriers to the type of information I collected during the interview; however, there did not appear to be any significant differences in the interviews conducted face to face than over the telephone.

I interviewed face to face several of the people who are involved in *Diseased Pariah News*. During a trip to San Francisco several of the members of the group and I met at the house in which the publication is produced. After initial discussions about the zine, I interviewed each person for approximately 90 minutes. I kept detailed field notes of my entire visit with the group. After the trip I spoke by phone with those members of the group who could not meet with me during my stay in California.

One difficulty that arose in conducting interviews was getting in touch with people who were originally involved with the publications. The combined factor of people moving on to other pursuits and the reality of people with HIV becoming ill, meant there were a lack of respondents who could speak on the early history and origins of the older publications in the study, particularly *Body Positive* and the *BCPWA News*. Some of the details about this history are contained in the texts of the publications; unfortunately, they tend not to be in-depth or personal accounts.

A total of fifty interviews were conducted for this study. The number varied with each of the publications. With the *BCPWA News* I interviewed eight people. Three were members of the staff at the BCPWA Society and the remaining five were volunteers. All of interviews were with men. The volunteers were HIV positive but the staff members did not disclose their

HIV status. I conducted nine interviews with people involved in *Body Positive*. Five of the respondents were men and four were women. Of the nine, seven were staff members at Body Positive and two were volunteers. Four of the nine disclosed as HIV positive - two staff members and two volunteers. Eleven interviews were conducted with people associated with or involved in *The Positive Side*. Eight of the interviews were conducted with members of *The Positive Side* collective. The remaining interviews were conducted with staff members of CATIE and people who had written for the publication. Of the eleven, nine interviews were conducted with men and two with women. Seven people disclosed as HIV positive. Ten interviews were conducted with people involved in the *Treatment Information Flash* - six were volunteers and four were staff members of the Hamilton AIDS Network. Three women and seven men participated. Three of the ten respondents disclosed as HIV positive. I conducted six interviews during my contact with those involved in *DPN*. All of the interviews were with gay men and all but one disclosed as HIV positive. Six interviews were conducted with those involved in *POZ*. All of the interviews were with men - none disclosed their HIV status. Four of the interviews were conducted with employees at POZ - two interviews were conducted with interns at the magazine.

Once most of the interviews were finished, I returned to the publications and began to read and code them in a more organized and systematic fashion. At this time my involvement in field research and in conducting interviews became less of a priority. I began concentrating more on coding the data, beginning the analysis, and starting to plan out the structure of the written work. The coding and analysis were guided first and foremost by the two aspects of community-based publishing defined by the methodological framework of the study: the

production and the content of the print media. All the sources of data, my field notes included, were examined in relation to these two issues or questions. The analysis was based on the emergent themes regarding the content and production of the print media.

Writing about PWA media created more methodological problems than I had anticipated. The main issue was finding a way of depicting all the publications as a single type of alternative media without obscuring or inadequately acknowledging the unique aspects of each publication. Using the themes of production and content were useful to a certain degree; however, through the data collection more substantive themes emerged that were not entirely consistent with this initial framework. For instance, it was evident that the historical evolution of print media in relation to the PWA movement was an important issue but did not fall directly into either production or content. Also, the role of publications as a forum for treatment information by and for people with HIV/AIDS was also a central theme but similarly did not relate directly to production or content. In response, I had to refocus my analysis in order to take into consideration the themes that emerged from the data. This variation meant that I had to alter the framework that I had started with at the beginning of the project. A second difficulty in composing my analysis was taking into consideration all six publications in each chapter. For instance, I simply did not have the space to look at the historical evolution of all six publications. Even dividing them into types - newsletters, treatment publications, and general interest magazines - made the analysis too broad. In addressing this problem I found that certain types of publications leant themselves to the particular question or issue that I was interested in examining. For instance, newsletters have the longest history; hence, they were an ideal case study of the link between the PWA

movement and PWA media. Similarly, the general interest magazines have tended to focus on portraying the lives of people with HIV/AIDS; hence, they were suited to an more in-depth analysis of how PWA media have struggled over what it means to be a person with HIV/AIDS. Looking back, it was surprising to me how essential writing was to the research process. Often in discussions of methodology, attention is devoted to the methods used and the process involved in coding and analysing the data. The task of writing the analysis is often taken for granted. In this case, however, the analysis emerged through the written work.

Limitations

The methodological approach that I have taken to this research has its shortcomings. The limitations that I can identify fall into two broad categories. The first relates to the process involved in selecting the publications that are a part of this project. I chose the six publications included in this research because they reflected the diverse range of PWA media that is currently being produced. In order to have this range, it was necessary to approach a diversity of AIDS groups located across North America. This raises serious concerns about the extent to which it is possible to compare PWA media with such divergent characteristics. Apart from *Body Positive* and *POZ*, which are based in New York, they are all located in vastly different social contexts. For instance, can you compare PWA media that are produced in San Francisco, California and Hamilton, Ontario? The people and resources that each group has to draw on varied greatly.

I have tried to address this issue in a number of ways. First, in the analysis I try to take into consideration the differences and similarities between the social forces that influence

PWA media in Canada and the United States. For instance, there are many similarities between the form that community-based AIDS organizing has taken in large urban centres, regardless of their location in Canada or the United States. Similarly, the ideology informing the self help movement by people with HIV/AIDS has also crossed national boundaries in North America. Conversely, there are differences between social systems in United States and Canada which have had a significant influence on the character of AIDS organizing and PWA self empowerment in each country. For instance, in Canada there appears to be more direct involvement by government in funding and directing those programs and services offered by community-based AIDS organizations. The population differences in terms of density and character between Canada and United States has also meant that the AIDS epidemic, and the response to the epidemic by communities, have taken a much different form. For instance, the PWA movement in the United States has been more widespread than in Canada in part simply because of the greater number people living with HIV/AIDS in the United States. There are many distinctions that could be made between the AIDS movement in Canada and the United States. I would argue, though, that there are grounds for comparison, and I have tried to make these comparisons, always keeping in mind the social factors that make each instance of PWA media production distinct.

The second limitation relates to the way I have approached the use of qualitative methods as a means of understanding the process of media activism. Under ideal circumstance, I would have conducted field research with all the publications and I would have conducted face to face interviews with all of the people involved in the AIDS publications in the study. Unfortunately, I was not able to conduct these interviews because of time and financial

constraints. In the case of local organizations, it was possible to conduct field research and extensive face to face interviews with key people involved in each of the publications. With organizations in New York, Vancouver, and San Francisco it was much harder to gain access to the social world of each publication. When possible, I visited the publications and asked to be shown around, introduced to people, and conducted as many interviews as time permitted. For the most part, though, I relied on one key person in each publication to ask staff and volunteers who work on the publications if they would be willing to be interviewed about their involvement. Despite my efforts, it was difficult with the larger publications in the United States to speak to as many people as I would have liked. For instance, it was only after months of persistent phone calls was I able to talk to several of the writers and editors at *POZ*. However, given the size of the publications it would have been better if I had the opportunity to speak with more of the staff.

I would argue that even though the type of data collection varied considerably between publications, the methodological framework of the study was comprehensive enough to compensate for this shortcoming. The fact that I was able to speak with several people from each of the publications about the main themes in this research (production and content) provided the foundation for an extensive and detailed analysis. Furthermore, I was able to analyse all of the texts from all of the publications. This material provided information about the publications that I was not able to acquire through interviews or field research.

The last limitation that I would like to address is the greater attention spent on the production and content of the publications and the lack of attention to the audience and the way the readership uses the publications. Again, under ideal circumstance, I would have tried

to bring the perspective of those who actually subscribe and read the publication to bear on the issues that I examine in this study. While I try to examine issues around readership and uses from the perspective of those who produce the publication, the aspect that is absent from the analysis is the voices of those who consume, as opposed to produce, the publications. This approach makes it difficult to address the issue of whether anyone actually reads and makes use of these publications. This is a question that was raised throughout the study by those involved in PWA media projects. In retrospect, it may have been possible for me to integrate a reader response element into the study. In fact, this may have been the most practical and instructive part of the research for those groups involved in AIDS publishing. Given the resources required to produce a publication on an ongoing basis it is difficult to devote time and money to examine who is reading it and how it is being used. Unfortunately, a reader response component did not seem to be possible given the constraints placed on this research. Furthermore, there is an argument for looking at the consumption of AIDS publications as a separate study.

Conclusion

Approaches to methodology in the social sciences tends to fall into two camps: those who wish to foster an interpretative model for social research and those who wish to hold on to the idea that a scientific model can be adapted adequately to the study of the social world. Bourdieu (1996: 18) has recently commented on this methodological division within the social sciences:

> The positivist dream of an epistemological state of perfect innocence has the consequence of masking the fact that the crucial difference is not between a science which effects a construction and one which does not, but between a science which does this without knowing it and one which, being aware of this, attempts to discover and master as completely as possible the nature of its inevitable acts of construction and the equally inevitable effects which they produce.

In this chapter I have tried to provide a detailed account of the methods and the methodology used in this study. More than that, though, following through on Bourdieu's point, in this research I have tried to account for my acts of construction and the inevitable effects of this construction.

During the course of the project I have learned a great deal about the advantages and difficulties of taking an interpretative approach to sociology as a graduate student conducting research within a particular political context. In the end, this project was not participatory action research. Instead, I used some of the objectives of PAR as a guide for this research. I was less able or interested in sharing control of the research process or developing action initiatives that targeted social injustice. Instead, following the advice of Adam (1992), as quoted in Schneider & Huber (1992: xv), I have tried to conduct this research

> from the perspective of people with HIV/AIDS rather than from those who dominate cultural discourses and political and social institutions. In taking the point of view of persons living with AIDS [I have tried to] confront questions of who the research is for and to what end it will be put.

In terms of these questions I have tried to be pragmatic and approach this project as an academic requirement. At the same time, I have also tried through my involvement to be of help to those involved in PWA media projects, and in conducting this research, to shed light on the history and the process involved in media production.

CHAPTER THREE: LITERATURE REVIEW

Media activism by people with HIV/AIDS can be related to many areas of research in the social sciences. Rather than focus on one, my approach in this chapter is to situate media activism at the intersection of three aspects of the literature on HIV/AIDS. The first is studies of the community-based response to HIV/AIDS. This work provides the political context for the emergence and development of PWA media projects. It also identifies several trends in the AIDS movement that might be applied to the study of PWA media. Research on HIV/AIDS and the media is the second substantive area that is relevant to this study. The development of media projects by people with HIV/AIDS was partially a response to the mass media. As a result, studies on the mass media provide an overview of the social factors that led those infected and affected to organize and challenge prevalent myths and stereotypes about HIV/AIDS. The third area is research on the experiences of people living with HIV/AIDS. Much of the content of PWA media projects consists of personal accounts and narratives about what it means to live with HIV/AIDS. Research on this topic helps to identify the themes and issues that people have raised in their contributions to PWA print media.

I have divided this chapter into three sections. The first outlines research on the community-based response to HIV/AIDS. The second looks at literature on HIV/AIDS and the media. And the third provides an overview of research on people living with HIV/AIDS.

In each section, I address the contributions that this study will make to each of these substantive areas of research.

Literature on the Community-Based Response to HIV/AIDS

When the first cases of HIV/AIDS were reported, gay and lesbian communities were essentially alone in formulating an organized response to the epidemic (Winnow, 1992; Patton, 1990; Cain, 1993a). The conservative political climate during the 1980s meant that governments were indifferent to HIV/AIDS because the disease was seen to only affect gay men (Sears, 1991; Rayside & Lindqusit, 1992). In light of this neglect, grassroots AIDS organizations were forced into being the primary means of AIDS education and support during this initial period of the epidemic. Eventually, with pressure from activists and the growing perception of AIDS as a public health threat, governments in most industrialized democracies were brought into the fight against HIV/AIDS (Kirp & Bayer, 1992). In many countries, including Canada and the United States, a key component of the state's response was a commitment to supporting community-based AIDS organizations. By this time, a network of AIDS organizations was already in place, and the health care policies of most industrialized democracies had identified community health services as a cost efficient and effective means of providing support and education (Rayside & Lindquist, 1992; Sears, 1991). The nature of this institutional response has meant that AIDS organizations have not been replaced by government or privatized programs and services; instead, with government support, they have continued to be at the forefront of AIDS education, support, and advocacy.

From the time that grassroots AIDS organizations emerged, social scientists, many of whom were directly involved in these efforts, began writing about the community-based response to HIV/AIDS. Initially this work concentrated on documenting the formation of grassroots AIDS organizations given the lack of an institutional response to the epidemic (Patton, 1985; Altman, 1986; Arno, 1986). Since that time, research on various aspects of the community-based response to HIV/AIDS has expanded. Scholars have continued to trace the development of AIDS organizing (Patten, 1990; Altman, 1994; Clausson, 1989). Numerous studies have also been conducted on more specific issues related to the community-based response, like the rise of treatment activism (Epstien, 1991), local organizing (Carpenter, 1988; Cain, 1993a; Arno & Hughes,1989; Kessler et al, 1988), the role of volunteers in AIDS organizations (Chambre, 1991; Kayal,1993), the need for health promotion among AIDS workers (Trussler & Marchand, 1993), and the state management of AIDS organizing (Kinsman, 1992; Cain, 1993b). I have identified several themes in the literature on the community-based response to HIV/AIDS that relate directly to this study: (1) the political foundations of AIDS organizing; (2) its gradual formalization; (3) and, organizing among people with HIV/AIDS.

Political Foundations

The first theme, the political foundations of AIDS organizing, refers to literature that has examined how the presence of gay and feminist organizations and responsive lesbian and gay communities made the development of a community-based response to HIV/AIDS possible (Kawata, 1989; Cain, 1993a; Altman, 1986; Patton, 1985; Padgug & Oppenheimer, 1992;

Kayal, 1993). By the early 1980s, there was an organized gay and lesbian community in most large cities in North America (Altman, 1982; Kinsman, 1987). Activism during the 1970s led to the formation of a political ideology based on a gay liberationist critique of oppressive social institutions (Kinsman, 1987; Pawluch et al, 1994). Part of this politics included the development of local and national organizations as well as public spaces for gay cultural institutions such as bars, bath houses, social groups and gay and lesbian publications (Adam, 1987; Kinsman, 1987; Patton, 1985).

When the first incidents of AIDS were reported, gay men and lesbians had the organizational and ideological means to develop educational programs and outreach services for those who were most severely affected by the disease. The rapidity and success of this early effort was the result of the knowledge and expertise that gay men and lesbians brought from previous organizing and activism. Gay activists were aware of the homophobia that existed within the health care system; similarly, many lesbians (and gay men) could draw on a feminist model of organizing around health issues which emphasized self empowerment, peer support and peer education (Dreifus, 1970). The mobilization of volunteers, mostly from gay and lesbian communities, were also key to the success of AIDS organizing (Kobasa, 1991; Chambre, 1991; Kayal, 1993).

This 'prehistory' of AIDS organizing is important because it points to the ideological and practical resources that shaped the grassroots community-based response to the epidemic (Berridge, 1983; Berridge & Strong, 1993). As a result, the structure and aims of early AIDS organizations have been, as Kinsman (1991: 216) writes, "informed by gay movement politics and by the feminist health movement's emphasis on empowerment." Similarly, the

development of PWA media has also drawn on the ideological and practical resources available within organized gay and lesbian communities. For instance, in many cases those involved in PWA media are gay men who bring to their involvement a political analysis of interrelationships between gay sexual liberation and HIV/AIDS. As a result, in looking at PWA media, it is important to consider that they are also a product of the gay and lesbian movement.

Formalization

The second theme, formalization, refers to literature that has examined the evolution of the community-based response to HIV/AIDS. In work on formalization, several social and political factors have been identified as having an impact on the structure of AIDS organizing. Perhaps the most fundamental change has been the gradual formalization and depoliticization of the community-based response to HIV/AIDS. The main force contributing to this shift, it is argued, is the increasing involvement of the state and health professionals in community-based HIV/AIDS services and programs (Cain, 1993b). This institutionalization has been noted in studies of AIDS organizing in the United States (Patton, 1990), in Canada (Cain, 1993b) and in the United Kingdom (MacLachlan, 1992). [1] This research has noted that the formalization of AIDS service organizations has been criticized because it contradicts the earlier and more political forms of AIDS organizing based on gay liberation politics, community development and self-empowerment (Segal, 1989).

In Canada for instance, Kinsman (1991) has argued that the rhetoric of community partnership as expressed in the National AIDS strategy, creates a situation in which AIDS

organizations have few options when deciding whether to serve the interests of the state and public health rather than those communities directly affected by the epidemic. State involvement at the level of consultation and guidance has meant that support, in terms of funding, would be allocated and controlled essentially by government agencies and bureaucracies (Cain, 1993b). This form of state management encourages AIDS organizations to adopt a model of service provision which contradicts the initial aims of the community-based AIDS movement (Kinsman, 1991; Rayside & Lindquist, 1992). As AIDS organizations become more like conventional voluntary health organizations, they are less able or willing to address political and social issues such as homophobia, racism, sexism and access to treatments (Cain, 1993). The provision of services also increasingly becomes professionalized which creates a division between those who are 'experts' and those who are 'clients.'

These formalizing and depoliticizing trends are useful when looking at print media by and for people with HIV/AIDS. Like the broader community-based response to HIV/AIDS, organizing among people with HIV/AIDS has also followed a similar course as governments have become more involved in support programs for those HIV infected (Brown, 1996). As a result, a key issue for my analysis will be the impact on this formalizing trend on the evolution, nature, and survival of media projects that are closely tied to organizing by and for people with HIV/AIDS.

Organizing by People with HIV/AIDS

The third theme in the literature on the community-based response to HIV/AIDS refers to studies that have been conducted on organizing by and for people with HIV/AIDS. Until

recently, there were very few studies that looked at the involvement of people with HIV/AIDS in the fight against HIV/AIDS. It is now more common to see articles and books published on the PWA self empowerment movement and on the involvement of people with HIV/AIDS in the community-based response to HIV/AIDS.

Central to this literature is an understanding of the political ideology which has served as the basis for organizing among people with HIV/AIDS. For Ariss (1996:136), this ideology was first articulated by a group of people with HIV/AIDS who attended a conference on gay and lesbian health in 1983 in Denver, Colorado:

> A manifesto known as the "Denver Principles" represents the earliest discursive fixation of this concept of "self-empowerment" for those with the disease. It presented a new strategy for the reorganization of the identity and collective social representation of people with AIDS.

The opening statement of principles outlined in Denver asserts that "we condemn attempts to label us as victims, a term which implies defeat, and we are only occasionally patients, a term which implies passivity, helplessness and dependence upon the care of others. We are People with AIDS." At the base of this ideology is the notion that those infected need to 'come out' as people with HIV/AIDS - a social not medical identity - and fight to become actively involved in those decisions that affect their lives (Callen, 1987). As Altman (1994:59) has noted, "in particular the 'Denver Principles' stressed the use of the term PWA as distinct from victims or patients and the need for representation at all levels of AIDS policy making to share their own experiences and knowledge." [2]

The Montreal Manifesto (1989) is a second important document outlining the principles of the PWA movement. It was declared by a group of AIDS activists at the 1989 International

AIDS Conference held in Montreal, Quebec. When people with HIV/AIDS were discouraged from participating in the conference, over 300 protestors from the HIV/AIDS community rushed the stage of the opening proceedings and declared the conference to be officially open. This symbolic gesture of taking control over scientific expertise was followed by a list of demands in the form of ten points that outlined the universal rights and needs of people living with HIV/AIDS. [3] The manifesto began with the preamble:

> HIV disease is a worldwide epidemic affecting every country. People are infected, sick and struggling to stay alive. Their voices must be heard and their special needs met. This declaration sets forth the responsibilities of all peoples, governments, international bodies, multinational corporations and health care providers to ensure the rights of all people living with HIV disease.

In many respects the Montreal Manifesto is an extension of the ideals set out in the "Denver Principles." However, there are elements in the later document that suggest changes in the PWA movement: there is greater emphasis on institutional accountability, more awareness of the international scope of HIV/AIDS, and the general tone is more militant, urgent, angry and explicitly political.

The political ideology of the PWA movement set out in documents like the "Denver Principles" and the Montreal Manifesto has helped to mobilize people with HIV/AIDS (Counter, 1996). Building on this initial grassroots movement, those infected have become involved in various forms of AIDS activism since the early 1980s. First, people with HIV/AIDS began to form their own community-based organizations. This organizing occurred first in large urban centres like New York, San Francisco, Vancouver and Toronto and then gradually expanded to include more remote and less populated centres (Rayside & Lindquist, 1992). PWA organizations have focused on providing people with HIV/AIDS with

practical support, such as financial assistance, treatment information and affordable alternative therapies, as well as on creating a supportive environment for people with HIV/AIDS to empower themselves by becoming involved in support groups and other self help programs. This mandate made sense given the model of organizing developed by many PWA groups. Patton (1990: 10) describes this form of organizing as,

> a hybrid between a gay liberation/identity model and the lobby/self-help model of such health-related groups as the Multiple Sclerosis Society ..., which similarly create micro-cultures of diverse people sharing a common medically-related experience.

PWA organizations helped those infected adopt and embrace a cultural and political identity, and a sense of community, by sharing their common experiences of struggling to live with HIV and AIDS. Much of the work on the development of PWA organizations has focused on the United States. Recently though, there have also been studies on the history of the PWA movement in Australia (Ariss, 1996), Canada (Roy, 1995), and internationally (Altman, 1994).

The political involvement of people with HIV/AIDS is not limited to community-based service organizations. AIDS treatment activism is the second aspect of the community-based response that has been shaped by the involvement of those HIV infected. Epstein (1991), for instance, has looked at how activists groups like ACT UP and AIDS ACTION NOW! have used political tactics to influence medical scientific practices around the development and evaluation of AIDS treatments. Similarly, Kuhn (1993) has documented the efforts of PWA groups to challenge the medical establishment in the use of experimental and alternative treatments through buyers clubs and community-based research. Looking at the PWA movement in Australia, Ariss (1996) has devoted several chapters to treatment activism

among those HIV infected both in terms of trying to influence the state and health care system regarding access to treatments and in the use of alternative therapies as a complement to conventional medical approaches.

Lastly, research about organizing among people with HIV/AIDS has also examined various types of cultural activism. Crimp (1987), for instance, edited a collection of works about AIDS activism that has focused on the political efforts of those infected and affected to transform the meaning of HIV/AIDS. As Crimp (1987:15) states in the introduction, this anthology brought together a wide range of cultural producers - critics, artists, people with HIV/AIDS, theorists, media activists - mostly who were gay and connected to PWA organizing of some form (whether ACT UP or the PWA Coalition of New York), in order to "show that there was a critical, theoretical and activist alternative to the personal, angelic expressions that appeared to dominate the art-world response to AIDS. What seemed to me to be essential was a vastly expanded view of culture in relation to crisis." Building on this work, a similar anthology, entitled *Fluid Exchanges* and edited by Miller (1992) highlighted the critical and activist works of artists in London, Ontario.

A focus on media activism by people with HIV/AIDS makes several contributions to this literature on the community-based response to HIV/AIDS. First, the content of PWA media is a way of looking at issues that have been prevalent in AIDS organizing generally, like formalization and accountability, in relation to the PWA movement. Second, media projects are a way of looking at the contributions of people with HIV/AIDS in the community-based response to HIV/AIDS. And third, in a related way, like treatment and cultural activism,

studying publications is a way of highlighting the ways in which people with HIV/AIDS have become involved in media activism.

Literature on HIV/AIDS and the Media

During the initial years of the epidemic the media effectively ignored HIV/AIDS. Homophobia, it has been argued, was the key reason why media institutions refused to treat HIV/AIDS as a serious health crisis (Watney, 1987; Nelkin, 1991). Eventually, the mass media did begin to cover the epidemic, after several prominent public figures, notably Rock Hudson, died of the disease. However, the messages regarding the epidemic tended to emphasize and reinforce prominent misconceptions about HIV/AIDS: that it could be spread through casual contact; that it was a gay disease; and that those infected were immoral and irresponsible. As a result, instead of raising public awareness, the mass media generally provided fuel for a mounting moral panic that contributed to the stigmatization of those infected with HIV. Only recently, after years of criticism, has the coverage of HIV/AIDS become more responsible and more responsive to the concerns of those infected and affected. However, despite these changes, HIV/AIDS continues to be consistently misrepresented (Dworkin & Wachs, 1998; Sacks, 1996).

In contrast to the mass media, it was the gay press that led the charge to raise awareness when HIV/AIDS first emerged. For instance, gay publications like *The Body Politic* in Canada provided information about the disease to those infected and at greatest risk of infection. Similarly, gay journalists began to write about HIV/AIDS in an effort to draw attention - from the gay community and from public institutions - to the gravity of the

HIV/AIDS epidemic. Apart from the gay press, however, alternative media were generally slow to respond to HIV/AIDS as a disease that not only affected gay men but marginalized and oppressed groups. However, as the severity of the epidemic became evident, and the media continued to misrepresent the disease, critics, writers, artists, and Leftist intellectuals did begin to respond critically to dominant AIDS discourse in their work (Lupton, 1994).

Unfortunately, literature in the social sciences has only examined the role of the mass media in representing the HIV/AIDS epidemic. Once the epidemic became a dominant theme in the media, scholars began to examine the way it was being reported. Most of this work has concentrated on media coverage in the United States (Bayer, 1991; Albert, 1986; Baker, 1986). Beyond this focus, though, there have been studies on the media in Canada (Clarke, 1991), Europe (Herzlich et al, 1989; Lester, 1992), Australia (Lupton, 1994; Ross & Carson, 1988) and in developing nations (Austin, 1990; Cunningham, 1989; Brieger, 1990). Of this work, most of the attention has been on the news media (Nelkin, 1991). Generally speaking, news coverage, more so than entertainment or popular media, is considered to carry more weight when constructing the 'truth' about HIV/AIDS. For instance, Nelkin (1991: 293) has argued that the impact of the news media has been significant because "besides affecting public perceptions, media reports on AIDS have also shaped the social context of the epidemic, personal behaviour, and policy agendas." The portrayal of HIV/AIDS in popular media and in entertainment media has also received attention, particularly in recent years. For instance, Erni (1992) looks at how the search for a 'cure' for HIV/AIDS has been taken up in contradictory ways in the popular press.

Much of the work on HIV/AIDS and the media has been devoted to exposing the myths and misconceptions about the disease. The general argument is that the mass media have misrepresented HIV/AIDS because too much emphasis has been placed on creating a spectacle in order to attract audiences and advertising revenue (Lupton, 1994). As result, the mass media is not effective in performing a democratic or informative function during a serious health crisis (Stroman & Seltzer, 1989; Reardon & Richardson, 1991). What is needed, it is argued, is for the media to become more accountable and responsible in their coverage of human affairs.

In addition to this general focus, research also addressed a range of more specific themes and issues. For instance, there has been work on audience perceptions of media messages about HIV/AIDS (Kitzinger, 1990; Cohen, 1991). Also, researchers have looked at comparisons between the coverage of HIV/AIDS and other diseases like cancer and heart disease (Clarke, 1992). Several studies have also been conducted on the broader social impact of media coverage, such as how reporting has contributed to a moral panic regarding HIV/AIDS (Lester, 1992), shaped perceptions of heterosexual transmission of HIV/AIDS (Dworkin, & Wachs, 1998), and influenced the development of public policy (Nelkin, 1991; Bayor, 1991).

In this literature there are two areas of research that are directly relevant to my analysis of media activism by people with HIV/AIDS: (1) research on the ways in which people living with HIV/AIDS have been represented in the mass media; and (2) critiques of how the media have used metaphors as a means of 'making sense' of the HIV/AIDS epidemic. Literature in each of these areas provides insight into the oppressive social climate that was created for

people living with HIV/AIDS as a result of the way the HIV/AIDS epidemic was represented in the mass media.

Representing People with HIV/AIDS

A common theme in the research on the representation of people with HIV/AIDS is that the mass media functions as a form of social control. This argument has been most convincingly made in relation to the messages conveyed about gay men and HIV/AIDS (Gronfors & Stalstrom, 1987). Watney (1987), for instance, has examined how the media contributed to twinning the threat of HIV/AIDS as a health crisis with the threat of gay sexuality as a moral crisis. The result was a view of gay men with HIV/AIDS as not only perpetrators of the AIDS epidemic but also as the cause of the decline of conservative middle class values and institutions. In a similar vein, Albert (1986) has looked at how the media portrayed gay men as deserving or responsible for their infection. In the media, HIV/AIDS was seen to be a product of a 'deviant' and 'highly promiscuous' gay lifestyle. These messages contributed to the stigmatization of people with HIV/AIDS on the basis of the deep seated fear and loathing in our culture toward homosexuality as immoral and unnatural. This moral rhetoric became a dominant motif in the way in which people with HIV/AIDS were portrayed in the media - homophobia became the basis for AIDSphobia. For instance, those who clearly contradicted the accepted image of the gay man with HIV were portrayed as innocent victims; women, children, and hemophiliacs with HIV/AIDS were exempt from blame because they were seen to embody middle class conservative values.

This logic in the coverage of people with HIV/AIDS created and reinforced a division between those who were guilty and immoral and those were innocent and virtuous. The policing of gay sexuality through the media was extended to include marginalized or oppressed groups in general. As studies have indicated, not only were gay men with HIV/AIDS maligned in the media, so were injection drug users (Sacks, 1996), prostitutes (King, 1990), ethnic minorities with HIV/AIDS (Lester, 1992), and anyone who was considered to be promiscuous according to middle class standards (Dworkin & Wachs, 1998). In each of these cases, HIV infection was associated with deviance in terms of behaviour, lifestyle, or social background. As a result, this transgression was considered grounds for punishment through moral sanctions or death (Sontag, 1989). As Patton (1990) has argued, the media's coverage of HIV/AIDS has lent support and legitimacy to coercive measure such as mandatory testing and quarantine as possible ways of managing the threat that those infected posed to public health and the social fabric.

AIDS as a Metaphor for Death

Studies that have been critical of the use of popular or spectacular metaphors in representing the epidemic are a second important area in the literature on HIV/AIDS and the media. Sontag (1989), for instance, has pointed out that the distinction between disease and health is deeply entrenched in the cultural values of most societies. The division between the two is not benign; health signifies the positive and good whereas disease is associated with decline and decay. As a result, reproducing the dominant social and moral order means sustaining the separation between the healthy and the diseased. When a health crisis emerges,

institutions like the media tend to rely on such dominant cultural logics and divisions in order to make sense of illness and death.

Once it was evident that HIV posed a threat to the general public, the fear and panic associated with prior plagues and health epidemics were used as a frame of reference for representing the HIV/AIDS epidemic. As Crimp (1987) has noted, the most notorious example is the use by the media of photographs of men in the late stages of syphilis by the media to portray gay men with HIV/AIDS. As a result, the dominant view of HIV/AIDS that emerged emphasized how the disease was highly contagious, not well understood, terminal and potentially more devastating than any prior epidemic (Lupton, 1994). As Conrad (1994) has argued, such representations twinned HIV/AIDS with death and thus reinforced divisions between the healthy and the diseased. As a result, images and stories in the media about people with HIV/AIDS tended to focus on contagion and death (Bayer, 1991). Currently, portrayals of those who are HIV positive in the media continue to focus on the inevitability of sickness and death even though it is now widely recognized that HIV/AIDS is a chronic and potentially manageable disease.

Resisting the Mass Media

This research demonstrates how the mass media have waged an assault against people with HIV/AIDS. As a key source of information about the disease, the media greatly contributed to the stigma, fear, and hatred toward those HIV infected, particularly during the period when the moral panic about the epidemic was at its height. As Lupton (1994) has argued, "[at] the beginning of the epidemic then, AIDS was rhetorically framed ... as a lethal,

violent, enigmatic, plague like disease caused by homosexual deviance." In addition to shaping misperceptions of HIV/AIDS among the general public, the negative and discouraging messages conveyed in the media also contributed to sentiments of futility and hopelessness about the possibility of survival for those infected. It is in this context that people with HIV/AIDS, by organizing collectively, developed their own supportive and informative means of communication.

The coverage of HIV/AIDS in the alternative media has not been taken up in research in the social sciences. It is unfortunate that research has not been conducted on, for instance, the role of the gay press, particularly early in the epidemic, as providing an alternative understanding of HIV/AIDS than that represented in the mass media. [4] To my knowledge, the only work that has touched on alternative media and HIV/AIDS is Crimp's (1987) *AIDS, Cultural Analysis Cultural Activism*. This anthology brings together visual and written material that illustrates the way cultural producers have engaged in activism, and used demonstrations, the media, and the arts to resist conventional understandings of HIV/AIDS and to put pressure on those public institutions and private industries that have not been responsive or accountable to the needs of those infected and affected by the HIV/AIDS epidemic. It is significant, for the purposes of this study, that included in this anthology are selections from *Newslines*, the first newsletter by people with HIV/AIDS. According to Crimp (1987: 5), these selections are examples of "cultural practices actively participating in the struggle against AIDS" that are necessary "given the failure of government at every level to provide the funding necessary to combat the epidemic."

My analysis builds on Crimp's work in that I am studying print media by and for people with HIV/AIDS that have occurred since *Newlines*. Analyzing these projects makes several contributions to the literature on HIV/AIDS and the media. It shifts attention away from the mass media and highlights ways in which people with HIV/AIDS have used media to resist and transform the dominant meaning of HIV/AIDS. However, at the same time, the content of PWA media helps to illustrate how the activism of people with HIV/AIDS was in part a response to the representations of the epidemic in the mass media. And lastly, this study points to the need in the social sciences for research that examines alternative media practices generally.

Literature on People Living with HIV/AIDS

Over the past fifteen years, the social circumstances that affect people with HIV/AIDS have changed dramatically. Early in the epidemic, for instance, knowledge of infection often came when people experienced health problems that were associated with AIDS. In addition, the fear, panic, and ignorance regarding the disease created an oppressive and often degrading social climate for those infected with HIV. Since the early 1980s and particularly in recent years, this situation has improved. People are learning of their infection earlier, there are beneficial treatments available, and the stigma of being infected has decreased in its severity. Nonetheless, those infected still face obstacles and difficulties, particularly since HIV/AIDS has been most prevalent among those who are in some way marginalized or oppressed. More than ever, it seems, social issues like poverty, homelessness, racism, and homophobia are having a direct impact on the survival of people with HIV/AIDS.

Research on the social aspects of HIV/AIDS has concentrated on topics like AIDS prevention or the societal impact of the AIDS epidemic (see Graubard, 1990). Studies that focus on issues that are related to people living with HIV/AIDS have been much less prevalent. Research in this area started to develop in the early 1990s with several studies that focused on the experiences of people with HIV/AIDS and identified the need for further study (Weitz; 1990; Cleary, 1993; Whittaker, 1992; McCain & Gramling, 1992; Adam, 1992; O'Brien, 1992; Hunt, 1992; McCormick et al, 1993; Rabkin et al, 1993). [5] In recent years, there has been a flourish of articles and books on people living with HIV/AIDS. *AIDS CARE*, in particular, has been a prominent forum for research on this subject. In the past two years, for instance, this journal has featured numerous articles on a diverse range of topics related to people with HIV/AIDS (see New & Trickett, 1998). Similarly, after the 1996 International AIDS Conference, the *Qualitative Health Journal* devoted a special issue to the experiences of people with HIV/AIDS (see Barroso, 1997). In addition to these specific venues, it appears that social scientists generally are beginning to recognize the need for more research on people living with HIV/AIDS. [6]

This literature on people with HIV/AIDS has examined a range of topics. Prominent among these is the lived experience of HIV/AIDS. Research has examined how people with HIV/AIDS from different backgrounds and in different social contexts make sense of their lives. For instance, Shernoff's (1997) has looked at the distinct perspective of gay men with HIV in rural areas of the United States. Drawing on narratives about the experience of HIV, Adam and Sears (1996) have examined the personal, family and work relationship of those living with HIV/AIDS. On a more applied level, there has also been research conducted on

the health and social services that are available for people with HIV/AIDS. For instance, studies have been conducted on the lack of services for HIV positive women (Hackl et al, 1997; Simoni et al, 1995) ethnic minorities (Roberts, 1995; Siegel et al, 1997) and people with HIV/AIDS in general (Green & Platt, 1997). From a prevention point of view, studies have been conducted on people with HIV/AIDS in order to gain a broader understanding of how to reduce the rate of infection (Eckholdt et al, 1997). Gaston et al (1996:529), for instance, asked HIV positive gay men to provide information about their sexual practices in order to "analyse and determine the best predictors of safe sex practices [in order to] suggest public health interventions." [7]

There are several themes in this literature on living with HIV/AIDS that are particularly relevant to my analysis of media activism by people with HIV/AIDS. PWA media projects have been created as a forum for the experiences and knowledge of people with HIV/AIDS. Research that takes into consideration the perspective of those infected is useful when looking at how those involved in media projects have portrayed their own experiences of HIV or AIDS. I have divided this work into three areas: (1) research on the meaning of HIV/AIDS for those who are living with the disease; (2) studies that identify health and social issues that have been raised by people with HIV/AIDS; and (3) research on strategies for surviving HIV/AIDS.

The Meaning of HIV/AIDS

Relying primarily on qualitative methods, many studies have focused on the significance of HIV/AIDS for those living with the disease. A prominent theme in this work on the

meaning of HIV/AIDS is the changes that have occurred in people's lives as a result of their infection - particularly in relation to self perception (Slavin, 1994; Davies, 1997). For instance, Dunbar et al, (1998) has spoken with HIV positive women who have seen their infection as an opportunity for spiritual growth. Injection drug users have also talked about how they thought of HIV infection as a catalyst for "cleaning up their act" in order to take care of themselves and their dependents (Hassin, 1994). Not all of the transformations that people experienced were seen as positive. Sandstrom (1996), for instance, has examined the challenges that HIV infection has posed for gay men in terms of having to learn to redefine the meaning of sex, sexual relations and intimacy. Several studies have also examined perceptions of stigma and feelings of shame experienced by people with HIV/AIDS particularly in the context of intimate social relations (Wietz, 1990; Barnes et al, 1997; Alonzo & Reynolds, 1995). A central theme that emerges from this research is how the meaning of HIV/AIDS is closely tied to the challenges that people have faced while coming to terms with HIV infection as a part of their self identity. However, at the same time, as Aggleton (1996) has pointed out, despite this common element there is no single or dominant way of understanding the disease; each person with HIV/AIDS has a distinct perspective on the disease.

Health and Social Issues

In addition to lived experience, research has also been conducted on the concerns that are central for people with HIV/AIDS. In many studies, the stress of HIV/AIDS and the prominence of mental health problems has been identified as a major issue (Meyer et al, 1996;

Smith, & Rapkin, 1995). In particular, this question of stress and depression has been examined in terms suicide (Rabkin et al, 1993). Mancoske et al (1995), for instance, have argued that people with HIV/AIDS are at an increased risk for suicide because of the stress associated with the disease. However, studies have also argued that while HIV/AIDS is a source of stress and may lead to depression, this does not mean that people with HIV/AIDS have a higher rate of suicide (Pueschel & Heinemann, 1995; Catalan, 1995). In other research on mental health and HIV/AIDS, people with HIV/AIDS have identified the value of support groups specifically (Kalichman et al, 1996) and the need and importance of support services generally (Dean, 1995; Simoni et al, 1995; Hackl et al, 1997). A second important issue for people with HIV/AIDS is the difficulties that are posed by disclosure, confidentiality, and discrimination. Greene and Serovich (1996), for instance, asked questions about disclosure patterns found that many people with HIV/AIDS felt that there was too much information being made public from HIV testing sites. In terms of limits placed on access, Thomas (1996) has examined the difficulties that HIV positive athletes have faced in being excluded from participation in sport because of the risk of transmission. One of the central points that emerges from this work generally is that people with HIV/AIDS must contend with a broad range of issues - stress, health problems, discrimination and exclusion - as a result of their infection.

Survival Strategies

Research on people with HIV/AIDS has also explored the strategies and tactics that have been used in the pursuit of long term survival. A prominent theme in this work is the

importance of adopting a positive approach to living with HIV/AIDS (McCain & Gramling, 1992; Hunt, 1992). Crossley (1997), for instance, discusses how the people he interviewed explained their long term survival as a result of being either externally oriented (seeking forms of social support) or internally oriented (working toward self discipline and inner development) (see also Cowles & Rodgers, 1997 and Barroso, 1997). A second prominent theme is the use of alternative health care practices as a strategy for health promotion and health management. In studies by Pawluch et al (1994) and Whittaker (1992) people with HIV/AIDS identified the use of complementary therapies as being an important factor in their survival. On a broader scale, in a longitudinal study, Palombi et al (1997) found that long term survivors were those who generally had greater access to socio-economic resources. Along similar lines, Roberts (1995) has noted that the African American gay men with HIV/AIDS that he has spoken with often draw on their cultural heritage as a source of strength in surviving HIV/AIDS in the context of a racist and oppressive society. Studies by Durbar & Mueller (1995/6) and Gillman & Newman (1996) also came to similar conclusions regarding ways in which women drew on their life experiences as a source of strength and reliance in coping and surviving with HIV/AIDS. The value of this research, overall, is in highlighting the strategies that those infected have used to overcome these challenges.

Cultural Artifacts of Living with HIV/AIDS

The publications included in this study can be seen as cultural artifacts by and about people living with HIV/AIDS. They provide a forum for people infected and affected by HIV/AIDS to share their experiences and knowledge. Looking at PWA media in this way

contributes to the literature on experience of living with HIV/AIDS. In conducting this analysis, though, it is important to recognize that the way in which living with HIV/AIDS has been represented in PWA media projects has been informed by the political ideologies of the PWA movement. In this regard, the experiences conveyed in media projects represented the perspective of people with HIV/AIDS who are closely connected to the organized HIV/AIDS community.

Conclusion

One of reasons for looking at media activism among those HIV infected is it touches on several areas of research that have not been adequately addressed in the social scientific literature on HIV/AIDS. Research on the community-based response to HIV/AIDS, for instance, has examined organizing among those groups directly affected by the epidemic but has not adequately examined political organizing among those with HIV/AIDS. Similarly, there have been a great number of studies on the coverage of AIDS in the mass media, but very few, if any, on the representation of HIV/AIDS through alternative forms of communication. Lastly, research on the social aspects of HIV/AIDS has, until recently, largely neglected those issues and questions that are relevant to people living with HIV/AIDS. Instead, the focus has been on AIDS prevention and the problems that HIV/AIDS have created for the general populace. This study is positioned such that the findings will help to advance research in each of these areas of social research on HIV/AIDS.

FOOTNOTES

1. Beyond HIV/AIDS, research on the collaboration between community groups and the state generally have identified a similar trend toward formalization (Rodriguez, 1988; Schechter, 1982; Staggenborg, 1988; Marger, 1984; Piven & Cloward, 1977; Pearl & Riessman, 1965).

2. The full text of the "Denver Principles" has been reprinted in Crimp's (1987) anthology, *AIDS: Cultural Analysis, Cultural Activism*.

3. The Montreal Manifesto has been reprinted in full in Miller's (1992) *Fluid Exchanges: Artists and Critics in the AIDS*.

4. In the social sciences it appears that there is currently more openness to this type of research. For instance, in recent years, there has been a trend in media studies away from analysing the meanings conveyed in mass forms of communication. Instead, the focus has turned to questions of consumption, like the way audiences actively read the mass media, and to questions of production, like ethnographies of media organizations and corporations. Studies have also looked at how people are rewriting media messages through "textual poaching" and making more use of new media technologies (Stevenson, 1995).

5. One possible explanation for this delay is that researchers did not take an interest in the experiences of those infected until it became widely accepted that HIV/AIDS was becoming a chronic rather than terminal illness. Adam (1992), in contrast, has argued that sociologists and social scientists in general have simply been consistently late in terms of conducting research on topical or immediate issues and questions regarding the social aspects of HIV/AIDS.

6. While studies have increased since the 1990s, the bulk of research on the social aspects of HIV/AIDS continues to focus on issues unrelated to those living with HIV/AIDS.

7. Unlike most of the research in this area, studies that focus on prevention do not generally take into consideration the perspective or the needs of people living with HIV/AIDS. As such, they should be seen as an extension of the literature on prevention in studies of HIV/AIDS rather than part of the shift in emphasis towards research that is relevant to the lives and needs of people with HIV/AIDS.

CHAPTER FOUR: THEORETICAL FRAMEWORK

Over the past thirty years the use of alternative media has expanded dramatically. A main factor contributing to this growth has been the emergence of new political and collective identities among those who feel excluded from, even oppressed by, the dominant social order. Contemporary social movements - the feminist movement, the civil rights movement, the gay and lesbian movement, the peace movement, the environmental movement, the AIDS movement - have served as a catalyst, and provided a frame of reference for this type of media activism. Independently produced media provides a means of raising awareness among oppressed or marginalized communities while at the same time challenging the meanings conveyed by social institutions like the mass media and the state. At the same time, there also has been a gradual increase in public access to communication technologies. In practical terms, this democratization has made the use of alternative media possible. Like never before, personal computers, publishing software, fax, telecommunications, the internet, community radio and television provide the means for individuals and groups to participate in forms of cultural production previously reserved for an intellectual and political elite.

Media projects by and for people with HIV/AIDS can also be understood as being shaped by these recent social trends. The community-based response to HIV/AIDS has provided an organizational and ideological infrastructure through which those infected can become involved in media production. At this community-based level, activists have made use of

whatever range of media technologies that were available. Initially they relied on personal computers and photocopiers (often not their own), and gradually began to use more advanced publishing software and publishing technology, and more recently have turned to radio, television, video, film, the internet.

In looking at such projects the challenge has been how to theorize the use of alternative media among those involved in contemporary social movements. Social scientific literature on alternative media has acknowledged the political aspects of such communication projects. In many cases it is argued that what has distinguished alternative media from other forms of communication, like local community newspapers for instance, is their affiliation with some form of organized political movement. However, while the political aspect of alternative media has been examined, much of this work has been descriptive rather than theoretical. Recently, however, several researchers have used the work of Habermas (1989) on the public sphere as a way of making sense of alternative media in relation to political organizing among marginalized groups. I use this as a starting point in discussing the benefits of conceptualizing PWA media as an alternative public sphere that has been formed as part of the community-based response to HIV/AIDS. The idea of a mediated alternative public sphere, created and sustained by those involved in social movements, provides a conceptual guide for my analysis.

Literature on Alternative Media

Social researchers have been slow to examine the rise in the use of alternative media both by those involved in political organizing and in general. As a result, studies that have been conducted tend to be quite varied and dispersed across many different disciplines in the social

sciences and humanities. One of the main topics has been the dissident or alternative press. Armstrong (1981), for instance, has examined the rise of dissent journalism in the United States during the 1960s and 1970s. Seeger (1987) also examines a specific alternative publication, *The Berkely Barb*, and its transformation during political organizing by students in the1960s.

Research on the alternative press has also looked at political writing affiliated with specific social movements. Kessler (1984), for instance, has examined the publishing that occurred in association with organizing among women, workers, African Americans, and immigrants. Numerous more specific studies have been conducted on feminist print media, participation among women in grassroots publications (Riano, 1994), publishing among women of colour (Anzaldu, 1990), and differences between feminist print media and women's print media (Smith, 1993). In a similar vein, though to a lesser degree, researchers have also written about the gay and lesbian press (Weitz, 1984).

Most of the studies on alternative communication have focused on print media. However, there has been research on different types of media projects. Downing (1984), for instance, has written an extensive study looking at the political experiences of those involved in a wide range of alternative media projects (print, radio, video, television) in a diverse range of social and political contexts. And, as Knapper (1994) has noted, researchers are looking beyond print to the ways in which activists and collectives are making political use of a wide range of media formats.

The literature on alternative media, generally, has addressed a wide range of topics. However, as Downing (1988) has noted, there are several recurring themes that provide some

coherence to this area of research. First, it is common for studies to look at the style and content of alternative media, particularly in contrast to mainstream media. In a similar vein, a second theme is the distinctive ways alternative media are produced. For instance, in general those involved in alternative media projects tend to emphasize democratic decision making and value remaining autonomous and self managed. Lastly, research has also been concerned with the political nature of alternative media, specifically, as an expression of contemporary social movements.

A key shortcoming in this research on alternative media, generally, is the lack of attention to theorizing the function of such projects as part of a larger political and social project. Instead, the focus has been on concrete and specific issues. For instance, most studies of the dissident and alternative press, while acknowledging that they are products of broad social trends, tend to be largely descriptive, focusing on simply documenting the fact that alternatives to the mainstream print media exist. The exception is studies that have looked at the broader social, political, and cultural implications of alternative media; understanding such projects as integral to social movements directed at meeting the needs and interests of oppressed groups and working towards progressive social changes.

Alternative Media and Public Spheres

In recent years, as interest in alternative media has increased, more attention has been devoted to developing a conceptual basis in which to understand the use of media among those involved in social movements. For the purposes of this project I would like to focus on two studies that have paid particular attention to social theory. The first is Downing's (1988)

study of the anti-nuclear press in Europe. The second is Marshall's (1991) analysis of feminist print media in Canada. In each case, the study of alternative media is framed in relation to current debates regarding the role of contemporary social movement in transforming or revitalizing the public sphere in advanced industrial democracies. Both scholars use Habermas' writing on the public sphere as a foundation for their analysis; however, each approach this work from a different direction. Marshall builds on the feminist critique and reworking of Habermas to look at the political functions of print media in the women's movement. Downing, in contrast, looks at work that has applied Habermas' ideas to efforts by the working class to develop communication that is free from domination. Despite different influences, the two studies take a similar approach in terms of situating alternative media within a broader social and political context. This work is instructive in outlining a set of issues that provide a basis for looking at PWA media as a component of the community-based response to HIV/AIDS.

Habermas and the Public Sphere

For background, it is necessary to begin by discussing Jurgen Habermas' (1989) *Structural Transformations in the Public Sphere (STPS)*. This work traces the rise and fall of the bourgeoisie public sphere. As has been noted frequently the German term "offentlichkeit" does not translate well into English - the public sphere only partially captures what is a complex notion. As a result, its meaning has been the subject of debate. According to Habermas (1979:198)

> when we say public sphere we mean a realm of social life in which something approaching public opinion can be formed. Access is guaranteed to all citizens. A portion of the public sphere comes into being in every conversation in which private individuals assemble to form a public body.

In the abstract, the idea of a public sphere has several connotations: public access to openness; the opportunity to exchange ideas and opinions; public opinion; to act publicly; and, the formation of public debate about common concerns (Downing, 1988). Multiple meanings have made the concept of the public sphere ambiguous; however, generally, it can be thought of as the processes through which citizens are able to express and share their views and ideas about the public good, and as a result, participate in civil society.

For Habermas, though, working in a Marxist tradition, the public sphere has little value in the abstract; it is only meaningful in relation to specific historical contexts. This sentiment underlies the need for a historical perspective in *STPS*. According to Habermas, it is important to understand that the bourgeois public sphere emerged as a result of social transformations in Europe in the Eighteenth century. During this period the nature of political authority was shifting from private control (the church and monarchy) to public control (democratic elections and public opinion). Unlike prior forms of social organization, particularly feudal, this new social order required that citizens have access to the means of formulating and expressing public opinion regarding common concerns - particularly in relation to the use of authority, and the development of policies by the government. In *STPS*, Habermas examines the different ways in which public forums emerged in Europe to serve this purpose. In Britain people gathered in coffee and tea houses. In France citizens met in salons and clubs. In Germany reading societies became a popular venue for sharing ideas and opinions. Over time,

with the advancement of communication technologies, access to a public sphere became more mediated, shifting from clubs and societies to newspapers, radio and television.

Public forums like salons, tea houses, newspapers, enabled citizens of a particular class to shape public opinion and influence the state apparatus. As such, even though the public sphere was formed and controlled by an intellectual and business elite, for Habermas, the idea of access to public debate was essential to truly democratic societies. It served as a mechanism for civic participation in issues of common concern. The role of the public sphere secured a particular liberal bourgeois social order, but this was not grounds to dispense with the concept altogether; instead, broader access to personal involvement in public affairs was seen to be a beneficial objective to work toward.

In Habermas' analysis the decline of the public sphere is associated with the increasing colonization of public life by economic and market forces. It is problematic that in liberal democracies, legitimate authority is constituted by private (economically motivated) interests rather than by citizens acting through the state. Ironically, in advanced industrial societies, even though the potential for communication has increased it would appear that the means and relevancy of engaging in open public debate about common concerns has been co-opted. For instance, the emergence of cultural industries represents a threat to the potentially democratic role of the public forums like the media; consumerism and profit motive slowly displaces opportunities for debate and discussion about the public good. The decline of the public sphere means that citizens are less able to effectively influence the operation of public institutions.

Habermas wrote his history of the public sphere in the early 1960s; it was for many years

not considered part of his main contribution to social theory. However, when it was translated

into English in 1989 there was a renewed interest in the concept of the public sphere. Scholars

looked to Habermas as a means of conceptualizing changes in late industrial democracies that

suggested a revitalization of civil society even though it was still evident that public

participation in civil society continued to be in decline. A central issue is whether a revitalized

public sphere is possible given the extent to which social institutions have been privatized

under the logic of capitalist expansion and globalization. On one hand, there are scholars,

Habermas included, who viewed the potential for greater access to and participation in the

media - either through the use of new media technologies or through greater support for

publicly controlled media institutions - as contributing to a revitalized public sphere

(Garnham, 1987). Conversely, others commenting on Habermas argued that, while the media

can be a tool for social change, the most significant factor in the transformation of late

industrial democracies have been the rise of contemporary social movements. Activists have

used alternative media as a means of confronting social issues in the context of these social

movements. As Downing (1988: 165) notes, in West Germany,

> the ferment and turbulence of the 1960s and 1970s, and the numerous political
> movements of those decades pushed the attention of many political activists towards
> what could be *achieved* by mass communication projects and alternative media. Such
> groups were intent on pushing beyond a reaction of passive dismay at the seemingly
> inexorable encroachment of the power structure into the processes of public opinion
> formation (in Habermas' formulation ... the colonization of the life world).

In this line of thought, those involved in collective action, particularly in relation to identity politics, have challenged the colonization of the lifeworld by engaging in public debate through the formation of their own alternative public spheres. [1]

Alternative Public Spheres

Downing and Marshall do not rely directly on *STPS* as a means of further conceptualizing the idea of alternative public spheres. Instead, they draw on theorists who have taken up Habermas' work to look at the formation of alternative public spheres. [2] Their main criticism is that Habermas plays down and ignores forms of opposition to the dominance of the bourgeois public sphere. In looking at feminist print media Marshall turns to the recent work of scholars who have written about the exclusion of women from the bourgeois public sphere. Alternatively, in looking at the anti-nuclear press in Germany, Downing turns to the work Negt and Kluge (1983) which looks at the political potential of working class or proletariat alternative public spheres. Each of these attempts to extend Habermas provides a valuable perspective on the emergence and function of alternative spheres in the context of political movements, particularly in reference to the strategic use of alternative media.

For feminists writing about the public sphere, the central problem with Habermas' historical account is that it is founded on myths (Fraser, 1992, 1992; Felski, 1989). In other words, the ideas developed in *STPS* are useful but they overemphasize the importance of a particular bourgeois public sphere. McLaughlin (1993:599), for instance, has commented that

> feminist scholars cite Habermas's liberal model as both an idealization of an historical period of Northern European society and an exclusionary historical account that fails

to place importance on activity in spheres associated with women and other marginalized discursive communities.

Theorizing about public spheres, then, must take into consideration the struggles among groups outside and excluded from the bourgeois public sphere to engage in public debate and influence the structure of industrial democratic societies. One way of looking at the margins of the bourgeois public sphere is to focus on the alternative feminist public sphere that has been created through the women's movement both historically and in recent times. [3] Organized social networks of women, both informal and formal, provide the foundation for the formation of feminist public spheres. Marshall's concern, though, is not social networks but the use of media in the constitution of feminist public spheres. Periodicals, journals, magazines, electronic media like video, radio, television, and the Internet are spaces created by women for women; they are a means by which women share their experiences and articulate their views on topics of common concern.

Using Fraser as a guide, Marshall (1995:465) notes that "feminist media have carved out a significant space for the *development* of an oppositional public, within which the dynamics of identity-formation are critical to the outward challenges to official political discourses and structures." In looking at print media, one of key ideas that Marshall develops from Fraser is that feminist public spheres tend to function in two inter-related ways. First, they provide a forum for women to share their experiences and articulate their opinions on issues of common concern guarded from the influence of oppressive social relations. This dialogue allows women to support, educate and advocate for each other through the articulation of feminist political ideologies and collective identities. Second, alternative public spheres

challenge and attempt to reform the forms of domination that are embedded in social institutions and in social relations more broadly. Marshall's analysis looks at how feminist print media in Canada have tried to fulfill this dual role and the barriers to feminist media given the current social climate of hostility toward feminism and the economic challenges of sustaining forms of cultural production that are outside of mainstream media industries.

Downing (1988) takes a slightly different approach in this comparison of how the anti-nuclear press in Germany and Britain has constituted an alternative public realm regarding the threat of nuclear energy and nuclear war. Instead of feminism, the basis for this analysis is Marxism - specifically through the work of Negt and Kluge (1983) on working class alternative spheres. Again, the dual function of alternative public spheres is evident in this work. According to Downing's (1988:161) reading,

> the text's fundamental problematic was that of classical Marxism: how does a class in itself become a class for itself? The authors sought a partial answer in the development of a 'counter' public realm which would enable 'the commodity of labour-power to 'speak' and to develop awareness,' and thus to avoid being reduced simply to the status of object in the production process.

In this view, alternative forums for workers, like trade unions, provide the infrastructure for the development of shared political identities and common political goals. Again, as Downing (1988:166) notes, the hope is that eventually this dialogue would pave the way for broader social reform:

> [Negt and Kluge] instanced trade unions as the most basic institution developed to meet this need. Their longer-term objective was the construction of a counter-sphere, but of an autonomous proletarian public realm in which the dissonant experience and knowledge of the working class could be freely voiced, exchanged, debated, developed. In turn this new public realm could be expanded to a point at which it might supplant the processes and structures of the bourgeois public realm.

Despite its limitations - mostly connected to romanticizing working class consciousness - this view is particularly valuable in highlighting the importance of autonomous communication and debate among politicized marginal groups as the foundation for articulating credible alternatives to social problems within advanced industrial democracies (as opposed to bringing about an idealized vision of social democracy). Furthermore, in applying this theory to the anti-nuclear movement in Europe, Downing (1984) makes his own valuable contribution in emphasizing the need to focus on the experiences and perspectives of those activists involved in organizing media projects as a more grounded means of understanding the nature of alternative public spheres.

For the purposes of this research project, it is fortunate that Marshall and Downing have drafted a useful conceptual approach that takes into consideration the broader social and political implication of alternative media. One of the shortcomings of this theory, though, (taken up briefly by Downing) is the lack of attention given to the struggle over power within and between public spheres. This oversight is evident in Habermas' *STPS* and in many subsequent works that use the concept of public spheres. Eley (1992) makes this argument in his writing on Habermas and the institutionalization of political cultures in the Nineteenth century. Gramsci's concept of hegemony, he proposes, provides a complementary means of reworking the public sphere in order to understand how it was a claim to power among the bourgeoisie, and at the same time, also fractured, contested, contradictory, and negotiated. Turning to Williams (1977:109), Eley defines hegemony as

> an order in which one concept of reality is diffused throughout society in all its institutional and private manifestations, informing with its spirit all taste, morality, customs, religious and political principles, and all social relations... .

While this is a good starting point it is important to take into consideration several refinements to this basic definition. The first is that hegemony is broader than a specific ideology or set of ideologies; it is a general process referring to an entire way of living and thinking that gives a particular social order its legitimacy. Second, hegemony is accepted implicity through persuasion and incorporation; it is not imposed through coercion. Processes must be in place to ensure that a dominant social order is seen by the body politic to represent legitimate authority; furthermore, alternatives to this dominant order must be diffused and neutralized. And lastly, hegemony is contested, unstable, contradictory and uncertain; as a result, it needs to be constantly in the process of construction and elaboration.

Hegemony theory fits nicely with the concept of alternative public spheres. It is through control over access to the bourgeoisie or dominant public sphere, and control over the ideas, debate and communication that occurs in this public sphere, that hegemony is continually being won and lost. In turn, alternative public spheres, formed through activism within social movements, are counter hegemonic. There are two aspects to this idea of counter hegemony. The first is that alternative public spheres pose challenges to the persuasion and incorporation that is involved in the construction and reproduction of a particular dominant social order; the ideas and debates highlight the problems, contradictions, inconsistencies, and gaps in the logic behind the dominant social order. More than that, though, alternative public spheres are counter hegemonic in that they must also construct their own alternative social order. Counter hegemony also refers to an entire way of living and thinking that needs to be seen as legitimate and credible, and that is contested, unstable and always in the process of being

constructed and elaborated. In this light, the study of alternative media involves looking at the way in which hegemony is contested, and, the way in which a counter hegemony is constructed.

Alternative Media and the Community-based Response to HIV/AIDS

The community-based response to AIDS was formed using the resources and strategies developed within the gay and lesbian movement and the feminist movement. [4] Developing alternative public spheres has been a key element in feminism and gay liberation. As a result, it makes sense that public forums for people with HIV/AIDS would emerge within the context of AIDS organizing ; they were almost built into the logic of the community-based response to HIV/AIDS. For instance, early in the PWA movement, gay men with HIV/AIDS relied on such political strategies because of their involvement in or proximity to the gay and lesbian movement and the feminist health movement. In forming an alternative public sphere, political organizing among people with HIV/AIDS sought to encourage: (1) more meaningful communication between those infected with HIV/AIDS; and (2) the development of strategies for self help and self empowerment that would address the needs and interests of those directly affected by the AIDS epidemic.

Print media by and for people with HIV/AIDS have played a key role in the constitution of this public sphere. On one level, they provide a means for sharing experiences and knowledge about topics that are relevant to the lives of people with HIV/AIDS. On a second level, they foster ideas, debates, and opinions about credible alternatives to the social issues and problems that are facing those infected and affected by HIV/AIDS. Media projects,

though, are only one aspect of a much broader alternative public sphere. Support groups, workshops, conferences, speaking bureaus, hotlines, videos, information clearing houses, community organizations, choral groups, artistic collectives, writing groups: this is only a partial list of the broad range of forums that have been created by and for people with HIV/AIDS. Initiatives of this type are generally intended to provide education, support and advocacy for those infected and are at some level associated with community-based AIDS organizations. For instance, one of organizations in this study, the BCPWA Society, for instance, describes itself as "being dedicated to empowering persons living with HIV disease and AIDS through mutual support and collective action."

The theoretical approach outlined in this chapter - which positions alternative media as constituting an alternative public sphere and constructing a counter hegemony - is well suited to this project. From this theorizing about social movement media I have identified several key points that are relevant in guiding the study of print media by and for people with HIV/AIDS.

Alternative public spheres, as aspects of contemporary social movements, have an internal and an external function. Internally, they provide the cultural means by which marginalized groups can articulate political ideologies and collective identities. In this sense it is possible for alternative public spheres to be a form of support and education. For instance, in the case of HIV/AIDS, sharing experiences and knowledge among those infected can be valuable in terms of redefining a positive HIV test as a social and political identity not just a medical diagnosis. Externally, the ideas and debates that are formed in public spheres also challenge public misperceptions, and ideally, can also influence state policy and social and

power structures within the dominant social order. Again, in the case of HIV/AIDS, debates by AIDS activists regarding the ethics of clinical trials have had an impact on the way in which AIDS treatments are developed, approved, and tested. In looking at print media, it is important analytically to keep in mind that the two realms are closely intertwined and interdependent. For instance, there is not a clear line that distinguishes between internal concerns relating to the needs and concerns of people with HIV/AIDS and external concerns relating to social and power structures that impact upon a response to the epidemic.

Alternative public spheres are autonomous forums for communication among marginalized or oppressed groups. One of the purposes of a public sphere is to create an environment in which people with similar political and social interests can share their experiences and knowledge in hopes of helping each other, but also, in order to form collective identities. This dialogue, in many respects, is based on a balance between inclusion and exclusion; those who are marginalized or oppressed need to retain control over the creation of and access to alternative public forums. At first glance this point may seem self evident; however, the question of identity and community membership can be a very complex issue within contemporary social movements. Struggles over the limits of political and collective identities, in terms of who does and does not count as a member of a particular community, can create difficulties for efforts, like media projects, that are directed at self representation.

The construction of an alternative public spheres is a counter-hegemonic project. First, it is important to understand alternative public spheres as being constructed in relation to the dominant public sphere. A public sphere about living with HIV/AID, for instance, is a

response to the 'official' discourse about HIV/AIDS represented in the mass media or reflected in the policies of the state with regard to the AIDS epidemic. PWA media projects, then, would seek to contest, challenge, transform, oppose and subvert misrepresentations about HIV/AIDS, or conversely, support and nurture those policies or stereotypes that are progressive in relation to the struggles of people with HIV/ADS. Second, alternative public spheres are always under threat of being incorporated and discredited by power structures. For instance, in the case of HIV/AIDS as the state and industry have taken a greater interest in the disease, the AIDS movement has come under pressure to temper its politics in order to appease state and institutional structures. Such forms of incorporation have also had an impact on the nature of alternative public spheres. Third, alternative public spheres have themselves the task of constructing a particular hegemony. For instance, among AIDS activists, there is a prevailing view of what it means to be a person with HIV/AIDS or how to approach social issues regarding HIV/AIDS. It is important to take into consideration the fact that this counter hegemony is also always uncertain, incomplete, and contradictory.

In this chapter I have tried to outline recent theoretical developments in the study of alternative media. This new field is important in terms of understanding the increasing use of media among the public. Theorizing the function of alternative public spheres as a component of social movements helps to draw attention to broader social and political issues that are relevant to the study of PWA media. My contribution has been to introduce hegemony theory as a means of drawing attention to the struggles over power that occur in the production of media projects. By seeing alternative media as counter hegemonic, this study moves away from the idea that alternative media as simply forms of resistance. Instead, in constructing

alternatives, such media projects are examined as a form of activism which is not only

oppositional, but also transformative and emancipatory.

FOOTNOTES

1. A good example of this political activism has occurred within the gay and lesbian movement. In the struggle for liberation, gay men and lesbians collectively formed social spaces - communities, organizations, media, clubs, sporting events - in which they could be publicly open about their sexuality in a safe and supportive environment (Adam, 1987). This alternative public sphere in turn provides the necessary social and cultural climate through which to work towards broader social changes in regards to homophobia and hetrosexism.

2. Like the ambiguity surrounding the term public sphere, numerous variations for what I have referred as an alternative public sphere have been proposed. For instance, Downing (1988) makes reference to an alternative public realm. Marshall (1991), in contrast, uses several terms interchangeably - oppositional public sphere, counter public, feminist publics. My rational for alternative public sphere is that 'alternative' implies not simply an opposition to power structures but a vision of how they may be reformed and transformed; in other words, they provide an alternative not just opposition. A similar distinction might be made between resistance and activism: resistance implies opposition whereas activism implies transformation.

3. Rather than subscribing to the idea of one overarching public sphere, as put forward by Habermas and other critical theorists, feminist scholars have pointed to the existence of many public spheres representing the diversity of needs and interests in late industrial capitalism. Furthermore, since there are multiple feminisms, instead of a single public, the feminist movement in fact has fostered the creation of multiple feminist public spheres. This emphasis on diversity has posed challenges to the coherency and solidarity of views and opinions within feminist public spheres and alternative public spheres generally.

4. The mutual interaction between the gay and lesbian movement, the self help movement, the feminist movement was not confined to the emergence of the AIDS movement. Instead, in many cases AIDS organizing has continued to draw resources from allied social movements, primarily the organized gay and lesbian movement.

CHAPTER FIVE: NEWSLETTERS

As part of a larger community-based response to HIV/AIDS, organizing by and for

people with HIV/AIDS has served as a basis for the development of an alternative public

sphere. PWA organizations are distinct from AIDS service organizations in that they are

based on a self help model and provide programs and services that are specifically intended

for people living with HIV/AIDS. Community-based PWA organizations have sponsored

workshops, retreats, conferences, meeting places, coffee houses, videos, books, posters, and

other public forums for the purpose of encouraging self empowerment and self representation

among those infected and affected by HIV/AIDS. In terms of print media, for almost fifteen

years, those involved in PWA organizing (also referred to as the PWA movement) have

produced a diverse range of publications, though most often they have taken the form of

agency newsletters.[1] Such programs and services generally have been designed to help

people with HIV/AIDS provide mutual support, education, and advocacy.

In particular, agency newsletters have played a significant role in the construction of an

alternative public sphere within the context of the PWA movement for many reasons. They

were the first type of media created by and for people with HIV/AIDS. In the early 1980s,

when those HIV infected began to organize, in many cases the first project that was initiated

was the development of a newsletter. As such, they have become one of the few artifacts of

the early PWA self empowerment movement. Also, newsletters have been the most enduring

type of media by and for people with HIV/AIDS. In many cases PWA media projects are in general transitory and unstable; like most alternative media they usually do not last. Not all newsletters produced by and for people with HIV/AIDS have endured. However, many that were part of an organization from its inception have survived and thrived. Lastly, newsletters are considered to be a resource for people with HIV/AIDS (and the community more broadly) and an emblem for organizations that are part of the community-based response to HIV/AIDS. As a result, they have been used as a means of informing people with HIV/AIDS and as a way of staying informed about that state of PWA organizing in North America and around the world.

This chapter examines the changes that have occurred in newsletters in relation to broad social transformations in the PWA movement and the community-based response to HIV/AIDS. Over the past fifteen years organizing among people with HIV/AIDS has undergone a period of tremendous growth. Research on the AIDS movement has noted that, in the case of AIDS organizations, such expansion is often accompanied by increasing formalization and depoliticization (Cain, 1993b; Patton, 1991). In my analysis, I look at this professionalizing trend in relation to PWA organizing, and by extension, the newsletters that are produced in the context of PWA organizations. Of particular interest is the impact of professionalization on the construction of an alternative public sphere. A second related concern is the extent to which expansion and formalization has contributed to the success and longevity of PWA newsletters. In prior research on alternative media, a common theme has been the precariousness of such projects. However, few studies have looked specifically at the reasons why most projects fail, and conversely, why some projects continue.

In looking at these issues, my analysis traces the historical development of two PWA organizations and their newsletters. The *BCPWA News* is a publication of the British Columbia Persons With AIDS Society, an organization that is self described as "dedicated to empowering persons living with HIV disease and AIDS through mutual support and collective action." *Body Positive*, the second newsletter, is produced by an organization in New York called Body Positive. The mandate of Body Positive is to "assist people when they first acknowledge the impact of HIV/AIDS in their lives. Our peer model of self help offers information and support to help people make optimal decisions that can increase life expectancy and quality of life." It is important to understand PWA newsletters in relation to their development as part of a PWA organization. Indeed, I would argue that the construction and representation of an alternative public sphere for people with HIV/AIDS occurs at the intersection between the media project and the sponsoring PWA organization. Furthermore, given the lack of research on the PWA movement, it is valuable to use agency newsletters (and interviews with those involved in the newsletters) as a means of looking at the historical evolution of organizing among people with HIV/AIDS.

This chapter is organized according to four broad periods in the evolution of the PWA movement. [2] In the first section I examine how organizing within gay and lesbian communities provided the political, ideological and material foundation for the PWA movement, and by extension the formation of service organizations and agency newsletters. The second looks at the initial grassroots phase of organizing among people with HIV/AIDS and its influence on the creation of agency newsletters. The third section examines the expansion of the PWA movement and the expansion of PWA organizations and publications.

And, in the last section, I explore how the trend toward professionalization has influenced the direction of PWA organizing and PWA print media in North America. [3]

Political Foundations: 1969-1983

Several scholars have made the point that gay and lesbian political organizing and community mobilization played a crucial role in the formation of a grassroots AIDS movement (Padgug & Oppenheimer, 1992; Patton, 1985). For instance, in his study of AIDS organizations in Ontario, Cain has noted (1993a: 21) that,

> the HIV epidemic in Canada first appeared in urban centres which had fairly well-developed and active gay communities. AIDS organizers were able to make use of gay and lesbian resources and the community infrastructure. In the early 1980s, Toronto had a wide range of gay and lesbian organizations, and these pre-existing institutions were used to organize a quick and coordinated response.

At the onset of HIV/AIDS, the availability of community resources, though limited, was fortuitous given the extent to which gay men were directly affected by the disease and given the slow response by governments and other social institutions to HIV/AIDS. Simply put, in Altman's (1994:21) words, "where an organized gay base was lacking it was much more difficult to establish AIDS organizations."

Just as gay and lesbian organizations and gay liberation and feminist ideologies were essential to the development of AIDS organizations, they were, by extension, also a key resource for organizing among people with HIV/AIDS in the early 1980s. In addition to already established AIDS service organizations, many PWA organizers relied on gay organizations and women's health organizations for guidance and support. The Vancouver AIDS Coalition, for instance, relied heavily on the gay and lesbian community in Vancouver

for support and was modelled after a women's health collective. Body Positive, similarly, was

started by a small group of politically conscious gay men with HIV and began initially in a

small corner of the Community Health Project, a gay and lesbian health collective in New

York City.

In terms of the media, scholars have also identified the presence of an established gay and

lesbian press as being particularly influential in developing a community-based response to

HIV/AIDS. [4] Cain (1993a: 21) argues that,

> the gay media in North America ... played an important role disseminating
> information about HIV/AIDS and in the development of the AIDS political
> movement. [AIDS] workers ... have used the North American gay press to keep
> abreast of the medical, social, and political issues associated with the epidemic.

In the United States, other scholars have expressed similar sentiments regarding the role that

the gay press has played in AIDS organizing. Padgug & Oppenheimer (1992), for instance,

cite the work of Larry Kramer and other gay writers as successfully mobilizing gay

communities in response to HIV/AIDS. This point has been extended to locales beyond a

North American context. Altman (1994:21), for instance, has written that "the crucial role of

the gay press has not been confined to the developed world: in India and Indonesia (and I

suspect in some Latin American countries as well) the emergence of a gay press was an

integral part of the development of early community HIV work."

The existence of gay and lesbian media was also a resource in the development and

continuation of PWA media projects. [5] In developing the format and purpose of

newsletters, for instance, people with HIV/AIDS were able to draw on the heritage of

community-based publishing within the gay and lesbian movement. Publications like *Body*

Politic and *Angles* in Canada and the *Advocate* and the *New York Native* in the United States

provided a framework upon which to base agency newsletters, like *Body Positive* and the

BCPWA News (then titled the *Vancouver PWA News*). As such, they aspired toward being

both a community-service publication (information about local resources and AIDS

organizing) and a magazine about HIV/AIDS (personal accounts, stories and articles about

the experience of living with HIV/AIDS). These two themes have predominated, to varying

degrees, throughout the history of PWA organization newsletters. [6]

Grassroots PWA movement: 1983-1988

In the early 1980s, during the initial years following the formation of AIDS service

organizations, people with HIV/AIDS began to articulate their own political ideology and

their own strategies for collective action. In recounting the early years of the PWA

movement, Rosett has remarked in *POZ* that "too often people mark the beginning of AIDS

activism with the founding of ACT UP. But by then a generation of PWAs had already died

fighting for their lives." Frustrated and angry with the way the media, government, health care

system, and the general public were treating people with AIDS and ignoring the severity of

the AIDS epidemic, groups of politically conscious gay men with AIDS began to organize

coalitions. Eventually, in 1983, PWA organizers from New York and San Francisco met to

collectively articulate a political strategy for people with HIV/AIDS. In 1997, the last

surviving member of this group recalled this initial political action for *POZ* as follows:

> The PWA self-empowerment movement ... was officially born in June 1983 at the
> National Lesbian and Gay Health Conference in Denver, Colorado. For the first time,
> 11 gay men with AIDS made the case to some 400 health care workers that people

with AIDS were to play a leading role in all decisions affecting their lives. ... We marched in parades, testified before legislatures, started newsletters and hot lines, organized PWA coalitions. Against a barrage of medical reports that an AIDS diagnosis was a death sentence and media images of PWAs as disfigured monsters, we gave the most stigmatized disease of our time a human face.

This advisory committee made up of people with AIDS presented to the conference participants a declaration, called the "Denver Principles", that redefined those with AIDS as first and foremost 'people' rather than victims or patients. Building on this basic idea, the document listed a set of recommendations for health care professionals, all people, and people with HIV/AIDS. It also outlined the fundamental rights of people living with HIV/AIDS. Early activism among people with AIDS, like those who formulated and announced the "Denver Principles", provided the political and ideological foundation for the development of PWA organizations and for an expanded role for people with HIV/AIDS in the community-based AIDS movement.

Frustration with AIDS service organizations was another factor that led to organizing among people with HIV/AIDS. The programs available to people with AIDS were perceived to be too bureaucratic and not keeping pace with the changing needs and concerns of those HIV infected and affected. As Patton (1990:10) has noted, "the [PWA] movement was initially a self help movement which ran parallel to the emergent AIDS service organizations, but quickly grew into a coalition of local groups which were dissatisfied with the increasing bureaucratization of the AIDS service organizations." Establishing independent organizations was seen to be the most effective means of self empowerment and self representation. It enabled people with HIV/AIDS to educate, support and advocate for each other on their own terms, and, to become more actively involved in the fight against AIDS. [7]

The two PWA organizations in this study, the BCPWA Society and Body Positive, are examples of groups that formed during this initial period of the PWA movement. [8] Grassroots organizing among people with AIDS in Vancouver spanned roughly between 1984 and 1989. According to Brown (1997:51),

> the first PWA self help group began in October 1984 under the auspices of AIDS Vancouver. Meeting originally in people's homes and later at St. Paul's Hospital, the group officially separated from AIDS Vancouver in April 1986.

The name of the organization was initially The Vancouver PWA Coalition (most PWA organizations at this time used the term coalition). Only later did it become the BCPWA Society. The Coalition was the first PWA organization to form in Canada - it began officially in 1986 - and among the first in North America. As expressed in the *Vancouver PWA Coalition Newsletter* in November of 1986, the initial mandate of the organization was as follows:

> We are a Coalition of Persons with AIDS or AIDS Related Complex who have come together to find alternative ways of dealing with our dis-ease. About a year and a half ago the Coalition grew out of weekly support meetings people with AIDS and people with AIDS related complex held for themselves. It was felt that not enough was being done, and we knew that control had to come back to us, if we were to see positive changes in our lives. Taking back the POWER became one of the key principles of the Coalition.

During the initial years of organizing in British Columbia, AIDS Vancouver, the local AIDS service organization, was hesitant to engage in overt political protest for fear of jeopardising its government funding, and was slow to endorse alternative therapies as a health care option for people with HIV/AIDS. This inaction fuelled the efforts to organize among local people with AIDS (Kahn, 1993). In recalling these years, Kevin Brown, one of the founders of the Coalition, said that "we feel that very little would be done unless PWAs had a very vocal

presence and stood up for their rights." At this time the Coalition defined itself as a collective - distinct from, but in alliance with those groups involved in the struggle against HIV/AIDS (i.e. the local gay community and AIDS Vancouver). [9] In trying to put the principles of the PWA self empowerment into practice, PWA organizers, with limited resources, began developing basic education, support and advocacy programs run entirely by and for people with HIV/AIDS.

Body Positive was formed one year after the Vancouver PWA Coalition in 1987. In New York, unlike Vancouver, organizing among PWAs had been in existence on and off since 1983. As a result, Body Positive was a descendant of existing PWA coalitions more than it was an initial effort to organize among people with AIDS. Michel Hirsch, the founder of Body Positive, was involved in writing the "Denver Principles" and had helped to form the PWA Coalition of New York. On another level, Body Positive was also influenced by political organizing among people with HIV outside of North America. Patton (1990) has described this movement by people with HIV as follows:

> In Europe and Africa, community organizing centred around HIV infection: where the U.S. first developed People Living With AIDS groups, Europeans and Africans first developed 'body positive' groups. ... 'Body positive' organizing in the U.S. emerged after and in relation to the organizing in Europe. The U.S. organizing assumed that HIV-Ab+ (antibody positive) people have different issues than PLWAs, and for the most part, members feel that their issues are not dealt with by PLWA groups.

The catalyst for Body Positive, as Patton suggests, was the growing awareness that existing PWA organizations were not adequately meeting the needs and concerns of those who were HIV positive but did not yet have an AIDS diagnosis. [10] In November of 1988, Body Positive's first executive director described the organization's approach as follows:

Isolation is one of the worst terrors of HIV infection. Body Positive was founded fourteen months ago to give HIV positive people an opportunity to exchange information and emotional support and to create a community that would foster hope and dispel despair. Since then, hundreds of positive people have joined our support groups and educational seminars. Thousands read this newsletter each month. In 1989, we hope to expand our newsletter and to offer more workshops, support groups and public forums to try to meet the needs of the ever-increasing numbers of people testing positive.

By the end of the decade, Body Positive had moved out of their initial home in the Community Health Project and had established a series of programs organized around providing mutual support, education, and advocacy for those HIV infected and affected.

Publishing a newsletter, as a form of outreach, was included in the development of programs and services offered by Body Positive and the BCPWA Society during this initial phase of the PWA movement. Each publication, *Body Positive* and the *Vancouver PWA Coalition Newsletter*, were, like their parent organizations, grassroots endeavours. Generally speaking, they were created with two objectives in mind: to inform those who were part of the emerging HIV/AIDS community about the organization's development and operation; and, to support, educate, and advocate for people with HIV/AIDS.

The Vancouver PWA Coalition, immediately after its formal split from AIDS Vancouver, began its own publication. The inaugural issue (November, 1986) coincided with the opening of the Coalition's new office:

OPENING SPACE Hi! Right here in your hot little hands you hold the first ever issue of our newsletter. We in our collective wisdom, decided that it was time to get out information on what we were doing in a more systematic and organized way (well, at least we're trying). It is all part of carrying out our objectives, which are broadly speaking, to improve the quality of our lives in any way we can, whether through alternative therapies, group support, political activity and so on ad infinitum.

As a grassroots endeavour, the publication was disorganized, loosely structured and put together only using the agency's typewriter and photocopier. Volunteers were constantly in demand and encouraged to become involved. Each issue reiterated: "This is Your Publication. All are welcome to make this newsletter an excellent forum for our members and an up to date source of information to help us live our lives to the fullest potential."

At this stage, although the newsletter aspired toward being an up to date source of information, its content focused primarily on the Coalition's early development: articles focused on the organization's philosophy and mandate, committee reports, instructions on how to use services, fund raising events, times and dates when programs are available, ongoing forms of advocacy, and so on. The publication was used to raise the profile of the organization and to encourage those HIV infected or affected to become involved. For instance, each issue reported on advances in the PWA movement: "let's now prepare to make a strong showing again next year at the International Conference on AIDS in Montreal. In the meantime, let's keep reminding 'them' that 'we' are there ....." Repeated calls for action were peppered throughout the pages: "all of us possess talents that we can share. Whether it be computer skills, organizational abilities, or exotic talents, the Coalition encourages all members to come forward and help us maintain our strength and services."

Not all of the material in the publication focused on the organization, though. For instance, a list of local HIV/AIDS resources was compiled, published, and regularly updated. Articles on developments in treatments and the use of treatments (AZT was just becoming available at this time) were also included. Occasionally, those closely linked to the organization contributed personal accounts of living with AIDS. In 1986, Kevin Brown wrote

a series of articles called 'AZT and Me' about his use of what was then an experimental medication:

> It has been three weeks now since I first started taking the experimental drug AZT. [There has been] much publicity and hoop-la! It was an important moment in my battle against AIDS - a fresh chance, new hope, maybe a returned future. ... I am optimistic about this new drug. I believe it will make a positive change and maybe believing is half the battle to a cure.

The addition of useful information and personal accounts was the first indication that the newsletter might also become an informative, relevant, and safe forum for Coalition members and the emerging HIV/AIDS community in Vancouver and British Columbia. [11]

In the case of *Body Positive*, the idea of a publication devoted to the HIV community was considered from the very beginning to be part of the core programs offered by the organization. The vision for such a magazine came from Robert Massa, the founding editor of *Body Positive*. Massa recognized that few efforts were made to provide information to people who had recently tested HIV positive when he was working as a writer for *The Village Voice*. In 1987, he joined with Michel Hirsch and was the editor of *Body Positive* until 1989 when he became the AIDS editor at *The Village Voice*. During these years the editor was entirely responsible, with input from the few others directly involved in the organization, for the work of producing the magazine. Emphasis was placed on encouraging those who were part of an emerging HIV community to contribute their articles, personal writings, and announcements. However, it was evident, like in the case of the *Vancouver PWA News*, that much of the material included was written and compiled by the editor or by those closely involved in the organization.

Body Positive was considered to be an agency newsletter, although it aspired to be a magazine about HIV for seropositives. There were regular columns on the development of the organization, announcements for fund raising events and socials, times and dates for programs and services, pleas for the HIV community to become involved, and other news and information about Body Positive. Even though one respondent referred to *Body Positive* at this time as 'newsletterish' it did not look like a conventional agency newsletter. It looked, instead, like a magazine that was produced with limited resources. Each cover featured an illustration about a theme related to HIV/AIDS. For instance, in an issue about disclosure, the cover was a drawing of two men in bed together just as one notices a series of bottles containing AIDS medication on the nightstand. Between the covers, the publication was a more or less random digest of useful information about HIV/AIDS (treatment options, testing legislation, rates of infection, health promotion), personal accounts of living with HIV (stories of testing positive), and feature articles or stories about HIV, usually political in nature, either written by the editor or reprinted from another gay, PWA or AIDS publication. At the end of each issue there was a list of local resources for people infected and affected by HIV/AIDS.

Making *Body Positive* into a magazine, as opposed to a newsletter, was arguably a product of Massa's background as a gay journalist with *The Village Voice*. He was influential in shaping the publication's initial tone and format. However, the publication fit tightly into the mandate of the organization during this early period. Body Positive was just in the process of forming and developing programs designed to reach out to people with HIV/AIDS - many of whom were recently diagnosed. As a result, the publication sought to be both a newsletter

and a magazine. The newsletter was used as a means of promoting a newly formed grassroots organization. However, this was often overshadowed by the outreach objective of the magazine. Copies were sent to members of the organization, as subscribers, but the majority were distributed to HIV testing sites and used by staff in orientations and educational seminars. It was thought that the magazine should not be too much like an agency newsletter; but, this was hard to achieve with limited resources. The rationale was that if the publication appeared too preachy or institutionalized - like it was from public health or a health service organization - then people might be less inclined to pick it up, read it, and take it home. As a result, *Body Positive* tried to attract attention by having an edge and by having a tone that was optimistic and hopeful, introducing and reinforcing the idea that AIDS is not a death sentence.

In sum, during this grassroots period of the PWA movement, publications like *Body Positive* and the *Vancouver PWA newsletter* came into existence as loosely structured and roughly produced projects. Even though each publication had a slightly different function, they both expressed the youthful exuberance and collective spirit of grassroots PWA organizing. The tone, for instance, was informal and politically charged and the production emphasized participation over credentials. At the same time, though, they reflected the precariousness of the early PWA movement. With limited resources to work with, PWA newsletters appeared to be in a constant state of flux. The substance of issues varied considerably and they were rarely produced in a predictable or coherent fashion. Overshadowing this uncertainty was the sense that the development of a public sphere - in terms of PWA organizations and PWA media - would bring about the emergence of a

politically informed and politically active community of people with HIV/AIDS. And gradually as the PWA movement expanded, so did PWA organizations. This expansion had a direct impact on publications like the *Vancouver PWA Newsletter* and *The Body Positive* and on their role in constructing an alternative public sphere for people with HIV/AIDS.

Expansion of the PWA movement: 1989 - 1994

The PWA movement has continually grown since its inception in the early 1980s. Between 1989 and 1994 this expansion was particularly evident. Several broad social forces contributed to this growth, but two were particularly influential. First, in the late 1980s and into the 1990s the HIV/AIDS epidemic changed dramatically. Most significantly, a rising rate of infection, greater public awareness, and wider access to a test for HIV meant that the number and diversity of people who knew they were HIV infected grew exponentially. Not only were the number of people infected increasing, people with HIV/AIDS were also living longer and experiencing fewer immediate health problems. More and more people were learning of their infection sooner and had access to a wider range of health care options (conventional and non-conventional). It was becoming increasingly evident that HIV/AIDS was not necessarily terminal; instead it was increasingly being seen as chronic and manageable.

A second factor that had an impact on the PWA movement during this period was the emergence of a more concerted societal response to the epidemic, and to a lesser degree, the needs and concerns of people with HIV/AIDS. Governments, for instance, began developing strategies for funding community-based organizations to provide education and support

services (Bayer & Kirp, 1992). Also, in the area of medicine, advances were being made in the development of potential new treatments. Despite these advances, however, there were also many contradictory elements to this institutional response. According to Sean Strubb, founder of *POZ*, in the United States,

> Ronald Reagan's AIDS policies were an evil brew of malign neglect and cruel stigmatization. Talk of quarantine was in the air. The FDA took forever to approve drugs. Researchers ran pitifully few - often unethical or repetitive - trials, with no community input. The few promising drugs were priced beyond greed.

Similarly in Canada, medications were expensive and slow to be approved and released. And, it seemed evident that government policies, though arguably more benevolent than in the United States, still treated people with HIV/AIDS as a social problem given that actions like quarantine, mandatory testing, and registering those who test positive were seriously considered.

This societal response, combined with changes in the epidemic, had an impact on the PWA movement in several ways. It helped to create a climate of anger and hope within the movement as people with HIV/AIDS became aware of both the greater chances of survival and government inaction and lack of urgency. Also, the rise in infection rates led to a critical mass of people with HIV/AIDS interested in accessing and becoming involved in PWA organizations. At this time as well, the severity of the epidemic had helped to engender a growing awareness of the international impact of HIV/AIDS and the efforts to organize among people with HIV/AIDS in places outside of North America.

The Montreal Manifesto, declared by an uninvited group of people with HIV/AIDS at the opening of the Fifth International Conference on AIDS, held in Montreal, has come to

symbolize the political efforts of people with HIV/AIDS during this expansion period of the movement - in the same way that the "Denver Principles" has come to define the early grassroots PWA movement. Michael Slocum, the editor of *Body Positive* at that time wrote in January of 1990,

> for many, Montreal will be remembered as the moment when AIDS activism became an international force, when the human face of AIDS sent a message of urgency to the ivory towers of science and government. It was clear that this movement has come of age, and that the voices of those living with and affected by HIV/AIDS play a significant role in both public policy and speeding the progress of drug development.

The Manifesto outlined the universal rights and needs of people living with HIV disease and detailed the responsibilities of governments, international bodies, multinational corporations, and health care providers in responding to HIV/AIDS as an international health crisis, or pandemic.

This declaration helped to set the political tone for PWA organizing during this expansion period. [12] In North America, this mobilization and activism helped to create new forms of organizing among people with HIV/AIDS. An emerging political consciousness among those infected served as a catalyst in the development of direct action political groups like ACT UP in the United States and AIDS ACTION NOW! in Canada. [13] More specialized PWA service organizations were also developed at this time. For instance, those infected and affected by HIV/AIDS started organizations; groups by and for women, people of colour, injection drug users, and youth. This organizing among people with HIV/AIDS was directed at addressing the diverse needs and concerns of those infected and affected by HIV/AIDS.

During this period of expansion, existing PWA groups, like Body Positive and the Vancouver PWA Coalition, were transformed from localized collectives into an international network of more formal non-profit service organizations. To say that these organizations experienced tensions in trying to meet the demand for services among an ever growing membership would be an understatement. Though forms of funding (from government, the corporate sector, and the HIV community) were increasing, and more staff and volunteers were becoming involved on a consistent basis, PWA organizations were still struggling to keep up with the constant and quick expansion of the PWA movement and the HIV/AIDS epidemic.

By the beginning of 1990, the Vancouver PWA Coalition had established an initial organizational structure, a core set of programs and services, several staff members, an expanding membership, and a growing number of volunteers. This development was expressed in a letter of appreciation written in May of 1990 marking the death of Kevin Brown:

> To Kevin: You have been successful in so many ways. ... Your deeds live on now in so many others and especially with the organization you worked so hard to create. The concern that you had about your 'child' not surviving can be laid to rest. The PWA Coalition is solid now in structure and will continue to thrive as long as it is needed.

Several factors contributed to the coalition thriving, but arguably the most important was a significant increase in funding from the federal government ($129,000.00 over 17 months) at the end of 1989. It was part of the federal government's strategy to fund community groups that provide services for those infected and affected by HIV/AIDS. [14] Months after this funding was announced, the coalition changed its name to the Vancouver PWA Society - an

acknowledgement of its passing into a new phase of development, from grassroots collective to service organization.

In the 1990s the Vancouver PWA Society continued to expand at an extremely fast pace. The demand for services and the organization's membership steadily increased. In his ethnography of AIDS activism in Vancouver, Brown (1997:110) has remarked that

> while I was not able to obtain membership figures, the enormous growth of the organization is not difficult to believe. In 1986 there were just 15 members, and their principal fund-raiser, the Walk for AIDS, raised a mere $8,000 (Can). Eight years later there were just over 1,200 members who now work with a million dollar budget from a variety of sources including the state.

During this time, the Vancouver Society built on the education, support and advocacy programs that had been started in the 1980s. [15] For instance, the organization continued to offer workshops and retreats, facilitate access to complementary therapies, and build a resource centre. A notable addition to programs during this period was the development of an AIDS treatment project. It was started to help facilitate access to treatments and to help people with HIV/AIDS make more informed decisions about their health care. On an organizational level, the Society also began to facilitate organizing among people with HIV/AIDS in other areas of the province. For instance, the Victoria PWA Society was the first of a quickly growing network of AIDS and PWA organizations in British Columbia.

Body Positive underwent a similar transformation, from a coalition to formal organization, during this period of expansion. Ironically, as in the case of the Vancouver PWA Society, the Body Positive achieved some degree of stability and security at the same time as its founder, Michael Hirsch, died. On the eve of 1990, acknowledging Hirsch's contribution to the organization, the executive director at the time, Paul Wychules, wrote:

Body Positive is up on its feet. The magazine is expanding, educational courses will be offered more widely in the coming year, and our number of support groups continues to grow. Public and private funding sources are beginning to understand the importance of support and education (indeed AIDS prevention) for seropositives. The message Michael issued is being heard, and more and more people who test positive will be able to 'do for themselves' when it comes to learning how to take charge of their physical and mental health.

In the years following Hirsch's death Body Positive continued to expand. When it moved from the Community Health Project into its own office there were two staff positions, an executive director and a director of development. In the months leading up to the move, Ken Moore, the director of development, wrote to the HIV community for support:

Body Positive needs your help. The number of people coming to us is growing faster than our ability to service them. Consider this: just four months ago our twice monthly orientations attracted an average of forty people a piece. Our last orientation was attended by over 80 people. These increased numbers are reflected in increased costs. Space for support groups and educational seminars isn't free. Neither are any of the thousands of magazines we give away each month. Our office - which holds three staff and one or two volunteers at a time - measures 13 feet by 5 feet. We need a bigger one.

By 1993, the organization consisted of an executive director, an office manager, and six staff that coordinated volunteer operated programs like orientations, educational seminars, regular public forums on living with HIV/AIDS (medical information, insurance, personal finances, and so on), socials and dances, support groups, and workshops - all in different locations across the city of New York.

As Wychules foreshadowed, funding for Body Positive increased in size and scope in the years between 1989 and 1994. Initially, the organization was supported through funding from private foundations (like DIFFA, the Design Industry Foundation for AIDS), local AIDS service organizations (Gay Men's Health Crisis), community groups, fundraising events, and

individual donations. Eventually Body Positive received funding for its education, support and outreach work from the municipal and state governments, the New York State Department of Health AIDS Institute and the New York City Department of Health.

During this period Body Positive faced several challenges in providing programs and services for people infected and affected by HIV/AIDS. As an organization focusing on HIV, particular emphasis was placed on community development. This was increasingly difficult as the diversity of those infected increased. Attention was also devoted to expanding the scope of programs to meet the range of issues that people with HIV/AIDS faced - discrimination, negotiating the health care system, disclosure, safe sex, relationships, families, stigma, financial planning, and so on. Lastly, as a relatively new organization with a mandate that was in demand, efforts were directed at trying to provide services across the urban sprawl of New York.

To generalize, during this expansion period PWA organizations placed less emphasis on creating and sustaining a grassroots political movement - especially with the availability of new, and more consistent, forms of funding. Instead, attention was devoted to developing and fostering programs and resources that would make people with HIV/AIDS feel connected to a broader social community and help them make informed decisions about how to manage their infection and improve their quality of life.

Agency newsletters during this period reflected changes in the PWA movement. Publications like the *Vancouver PWA Newsletter* and *Body Positive* expanded in size and scope. As newsletters, they continued to provide information about their parent organization. However, gradually, they aspired toward being primarily a forum (regarding education,

support, and advocacy) for an emerging HIV positive community. In other words, expansion

meant that publications like *Body Positive* and the *Vancouver PWA Newsletter* were given the

resources necessary to move toward being more like a magazine by and for people affected

by HIV/AIDS than an AIDS agency newsletter. [16]

Between 1989 and 1994 the *Vancouver PWA Society Newsletter* matured as a publication

in several ways. The style and look of the publication improved as more resources were

available for computers, software, and a better photocopier. More significantly, though, was

the development of an expanded, standardized, and for the most part, consistent format. Early

in the 1990s, for instance, issues began to have the same front and back cover and the

different types of information provided in each issue - ongoing events, when the Society was

open, the availability of programs and services and volunteer opportunities - were given a

fixed location in the publication. Despite this initial organization, most of the information was

still displayed in a more or less random fashion. It was only in 1993 that the newsletter started

to have distinct sections (treatment information, letters to the editor, opinions, features

articles, and so forth), regular contributors, and a table of contents.

Expanding the publication and achieving consistency was an ongoing challenge. For

instance, the loss of an editor, which happened several times during this time span, was

particularly difficult. As a volunteer driven project, the editor was not only responsible for the

content and planning, he or she was also responsible for overseeing the production of each

issue. It was often several months before the newsletter recovered from the loss of an editor

because of the time required to find and train a new volunteer to take over the position. [17]

Establishing some degree of standardization was possible, to a large extent, because as

membership grew, more volunteers were available to work directly on the publication. For instance, in 1990 approximately 6 to 8 volunteers produced the *Vancouver PWA Society Newsletter*. By 1993, the number of core volunteers (those involved in editing, writing, and graphics) had doubled, and a total of approximately 25 volunteers were involved in producing each issue. [18] Some of these volunteers had previous experience with community-based print media, and as a result, brought specialized skills and dedication to the newsletter as a distinct program offered by the Vancouver PWA Society. [19]

Changes in the *Vancouver PWA Newsletter* in the early 1990s reached beyond the style and format. As part of a quickly expanding AIDS service organization the role of the publication was expanded in order to reach a growing membership - most of whom were not intimately involved in the organization. The newsletter became a means of informing members about the organization's operation and its programs and services. Members were encouraged to use the newsletter as a means of making their voices known and becoming involved, if at a distance, in the fight against HIV/AIDS. [20]

Turning the *Vancouver PWA Newsletter* into an information resource for people living with HIV/AIDS (i.e. as a forum for education, support, and advocacy) was not developed until quite late in this expansion period of the PWA movement. In terms of education, for instance, the publication gradually began to offer more practical advice about living with HIV/AIDS. In addition to advice about finances and legal issues, a significant proportion of each issue was devoted to treatment and health care information, which was consistent with the organization's general commitment to developing a comprehensive treatment project. In the area of support, more people with HIV/AIDS began to contribute stories and personal

accounts, not just about their own experiences with HIV/AIDS, but also about friends and lovers who were living with the disease. Much of this material was directed at engendering a sense of hope, community, solidarity, and accomplishment among those reading and producing the publication. [21]

Similar to the *BCPWA News*, between 1989 and 1994 *Body Positive* was hard pressed to keep up with the growth of its parent organization. For instance, during these years of expansion, the number of copies produced each month grew from 1000 to 15,000 with hardly any increase in support for the publication from the organization. It was evident, given the persistent calls for volunteers and donations, that given the available resources the magazine was constantly overextended. The large distribution was beneficial, though, in that it produced revenue for the magazine and for the organization. Using a magazine format, in each issue readers were encouraged to subscribe or donate in exchange for receiving the publication. The objective was to have the magazine sustain itself. As result, *Body Positive* was supported almost entirely by its readers.

With the support of readers, *Body Positive* was able to expand as a forum for education, advocacy, and support. This process was shaped by both changes in the organization and the involvement of key individuals. [22] Around the same time that Massa left the magazine in 1989, Body Positive increased in size and scope. As a result, the magazine was formally integrated in the organization's core programs and services. An advisory board was established to provide guidance in the magazine's development. The editor was integrated into the agency as a paid staff member rather than a volunteer. This person was responsible for coordinating all aspects of the magazine: planning issues, writing editorials, overseeing

the involvement of volunteers and staff, ensuring that the magazine is produced on time, and managing the subscriptions and donations from readers. All of these changes helped to bring a degree of stability, consistency, and legitimacy to the magazine, uncommon among many PWA publications at this time.

During this period the job of editor required a tremendous amount of time and energy; as a result, the editor has a significant influence over the direction and character of the magazine. As a result *Body Positive* was transformed incrementally with each successive editor. Between 1989 and 1993, Michael Slocum and then Jim Lewis were the editors for *Body Positive* (they co-authored "You Are Not Alone" an opening 'creed' that has become a trademark for the magazine and the organization). During their tenure, Slocum and Lewis built upon the format established for *Body Positive* by Massa during the first two years of its production. Looking back at the issues published during this period, it seemed that their main contribution was to make the magazine an integral part of the programs offered by Body Positive.

Changes made to *Body Positive* during this time were accomplished in several ways. First, the magazine was considered to be a form of community development - it was used more extensively in efforts to reach out to people with HIV/AIDS. Both Slocum and Lewis were firmly committed to the idea that people living with HIV/AIDS can and should have the opportunity to learn and support each other; hence, participation in the magazine by people infected and affected by HIV/AIDS was persistently encouraged. The key to this was fostering participation and communication. New sections were created specifically for the 'voices' of people living with HIV/AIDS and for profiles of Body Positive volunteers, all of

whom were infected or directly affected by HIV/AIDS. A personal column section was introduced called "Connections" which was designed as an opportunity for people living with HIV to meet. This became hugely popular. Letters to the editor frequently told stories of people who had met other people with HIV/AIDS through the column. In addition, on a regular basis the magazine profiled people who had met and fell in love (with happy and unhappy endings) as a result of responding to a personal ad in the magazine. A second factor bringing the magazine closer into the organization occurred when staff from the different programs in the organization (outreach, education, support) began to write regular articles. For the first time, an element of practical journalism for people with HIV/AIDS was introduced to the publication; though, since staff were also infected or affected, readers were addressed as peers rather than clients.

The changes introduced by Slocum and Lewis provided the foundation for the publication as a magazine. However, it was not exclusively a magazine. Elements of an agency newsletter continued, but became fixed in the format of the magazine: a column for the executive director, program listings, resource listing, organization announcements, job advertisements, fundraising advertisements, and so on. After Lewis, Jefferey Karaban, the director of volunteers, kept the publication going while a new editor was found. In an interview with me, he aptly summed up the state of Body Positive during this expansion period of the PWA movement:

> Michael Slocum was the first editor that I can remember. He got the political tone right, but the quality was not that great. It was a new magazine. It still had too much of a newsletter feel to it. And not such a discriminating eye in terms of editorial work. Jim Lewis improved on that when he took over. Just before he died I was

pressed into service and just coasted a bit - I alternated between coasting and drowning.

Particularly during times of organizational transition, it seemed, the magazine reverted back to being used as a means of informing organization stakeholders about the restructuring that was taking place.

To sum up, between 1989 and 1994, publications like *Body Positive* and the *BCPWA News* adapted as best they could to the tremendous growth in the PWA movement at this time. The result was that they moved in a similar direction as their parent organization: despite periods of precariousness and flux they expanded their role as strategies for communication between people infected and affected by HIV/AIDS. They became more legitimate forums for education, support, and advocacy. The introduction of more consistent funding, a larger readership, and greater involvement by volunteers provided the necessarily resources and stability that was required for the publications to develop as forums for education, support, and advocacy. In constructing an alternative public sphere, the publications were reaching out, shifting from an internal focus (those involved in PWA organizing) to one that tried to reach a broader more diverse community of people living with HIV/AIDS.

Formalization of the PWA movement: 1994-1998

Between 1994 and 1998 the PWA movement has continued to expand in response to increasing demand for services by those infected and affected by HIV/AIDS. Adapting to this expansion has pushed PWA organizations toward a professional model of operation and

service delivery in an attempt to be more accountable and more efficient. As a result, groups that began as collectives have become increasingly formal and bureaucratic. Ironically, for many years the PWA movement was defined in opposition to 'professional' AIDS organizations. However, despite some resistance to following in the footsteps of mainstream AIDS organizations, this move toward a more professional and institutionalized approach has appeared to have accelerated in recent years. [23]

Several scholars have examined the professionalization of the community-based AIDS movement, though in relation to mainstream AIDS service organization, not the PWA movement. [24] In broad terms, this work has argued that partnerships with the state have led AIDS organizations to become less political and more formal - this has made it more difficult for organizations to be connected to those communities directed infected and affected by HIV/AIDS (Cain, 1993b). In a Canadian context Kinsman (1992: 224) has described this situation as follows:

> State funding for community groups is a victory gained through political struggle. As the same time it is also part of how groups are 'guided' by federal agencies. These funding regulations work to 'depoliticize' groups, moving them away from contested, progressive activities and connecting them to the relevancies of particular state bureaucracies. ... Groups originally set up to empower PLWA/HIV and the communities most affected by AIDS can come to stand over these communities as part of a state-regulated process of management.

Patton (1990) has provided a similar analysis of the AIDS movement in the United States. MacLachlan (1992: 434) has noted that organizing in the United Kingdom initially based on self help and self empowerment has given way to "more formally constituted organizations, usually modelled on conventional, hierarchical structures."

This literature is useful in providing insight into the professionalization of the PWA movement in recent years. First, there has been a certain degree of consolidation between PWA organization and mainstream AIDS organizations. More efforts have been made to include those infected with HIV in all levels of the community-based AIDS movement and this has helped to reduce the division and divisiveness between AIDS organizations and PWA organizations. Roy (1995:32) has described this as the emergence of an new AIDS agenda: "people with HIV/AIDS are becoming more influential, better organized, and leaders of a new AIDS agenda for community action." As a result, PWA groups, by association, have had to adapt to the more formal structures of larger AIDS service organizations.

A second factor is that PWA organizations have fostered closer ties with the state. After years of advocacy, government polices are now more open to addressing the needs and concerns of people living with HIV/AIDS. More resources have been allocated to PWA groups to provide support and education programs (though prevention and research are still, by far, the priority of government agencies). Increasing 'state management' of PWA organizations has made them dependent on, and linked to, government bureaucracies. This reliance has led many people with HIV/AIDS to question the extent to which PWA organizations are able to sustain their commitment to those communities infected and affected when they are guided by and reliant on government agencies.

A third factor contributing to the formalization of the PWA movement is the growing investment by AIDS industries (like drug companies) in the lives of people with HIV/AIDS. The growth of AIDS industries has opened a new source of support for PWA organizing (and AIDS organizing more broadly). Private funding, particularly in the United States, is not a

new development; however, recently, it appears as if this support has increased in size and scope. It is not uncommon to see corporations providing support for AIDS organizations and foundations for AIDS care. [25]

Endorsements from ASOs, government, and the corporate sector have helped to advance the needs and concerns of people with HIV/AIDS. They have provided resources needed for PWA organizations to expand and develop programs for those infected and affected by HIV/AIDS. The establishment of partnerships has also led to a more formal and professionalized movement. Studies of professionalization within the AIDS movement have argued that this trend is accompanied by a degree of depoliticization as AIDS activism is co-opted by institutional forces. For, Larry Kramer - social critic and founder of ACT UP - writing for *POZ* in 1997, this means that,

> right now, we've got a bunch of dumb-ass AIDS service organizations more concerned with their mortgages than our mortality. More concerned with getting new donors than with getting new drugs. More intent on getting you to the next Carnegie Hall benefit for Elizabeth Taylor than on squeezing Bill Clinton's nuts until they exude a cure and a vaccine. These organizations have sacrificed urgency, action and anger in a pathetic exchange for careerism, corner offices, fancy cocktail parties and their names in Liz Smith's column.

It is debatable, though, the extent to which this same argument applies to PWA organizations. On the one hand, there are people involved in PWA organizing who suggest that the emergence of new treatments, with the potential to dramatically improve the life chances of people with HIV/AIDS, and the availability of state support for programs and services, has contributed to a less urgent and less overtly political stance among those involved in the AIDS movement. There are alliances now between PWA organizations and pharmaceutical companies that would have not been tolerated ten years ago during the height of treatment-

activism within the AIDS movement. At the beginning of 1997, after the Eleventh International Conference on AIDS in Vancouver, in response to the media's coverage of the benefit of new treatments, the Director of Body Positive, Linda Mayo, expressed some of these concerns:

> We are facing the real threat that public and private funders, individual contributors, and even people living with HIV will become complacent, sit back, and consider the war won. THE TRUTH IS WE MUST NOT BE COMPLACENT ON ANY FRONT! Now, more than ever, we must remain steadfast in our commitment to stay informed, question authority, and continue to advocate.

For activists like Mayo, the climate around HIV/AIDS has shifted such that there seems to be less of an adversarial stance toward the commitment of drug companies and other institutional stakeholders in the fight against HIV/AIDS.

However, unlike more mainstream organizations, there are people involved in PWA organizing who argue that the movement has retained a degree of political consciousness. As Kramer suggests, people living with HIV/AIDS are still subject to gross neglect, various forms of discrimination and inadequate access to essential services. This has helped to fuel a continued politics of HIV - 'a new AIDS agenda' - within the community-based response to HIV/AIDS. Hence, it is hard to know if, for instance, the use of drug company money is a form of co-optation or a strategic use of available resources - or both. Perhaps it is best to view this situation as an ongoing struggle over power - the incorporation of politically subversive elements of the PWA movement against efforts to re-politicize the epidemic in terms of the needs and interests of those living with HIV/AIDS.

As can be seen in the case of the BCPWA Society and Body Positive the process of professionalization has created issues and debates among PWA organizers that are still being

worked through. PWA organizations are still small community-based organizations when compared to many mainstream AIDS service organizations. Nonetheless, it is clear that they are grappling with the same social forces have led to the institutionalization of the AIDS movement generally.

In terms of the Vancouver PWA Society, in recent years its membership and mandate has continued to expand. For instance, in 1994, the organization changed its name again - to the British Columbia PWA Society - as its scope was broadened to include the entire province. [26] This change was made soon after the introduction of a Provincial AIDS Strategy and the announcement of the second phase of the Federal government's National AIDS Strategy. Increases in the breadth of the organization were accompanied by a burgeoning membership. In 1994, the Co-Chair of the Society, Micheal Eaton, wrote,

> The most overwhelming ongoing information that presents itself to the Society is the constant rise in memberships over the past months. In any given weekly period we are seeing an increase of up to 30 new members. This has resulted in a total membership of 1835 members, with more than 22 group memberships and approximately 600 associate members.

Currently, in 1999, the membership has exceeded 4000 and the Society is now the largest AIDS organization in Western Canada. It is difficult, as Eaton acknowledges in his report, for a community-based organization to constantly adapt to an ever growing demand for services: "this [rise in membership] is encouraging as it can be seen as a direct act of health promotion, as new members are prepared to come forward and enlist themselves as part of the society. However, this also translates and impacts directly on the society."

In response to the impact of expansion, the Society has fostered closer ties with the state and with local AIDS service organizations. For instance, in 1993, the Society joined with two

other AIDS organizations and formed the Pacific AIDS Resource Centre. The move was designed to make services more efficient, coordinated and centralized. In terms of financial support, the Society still receives a significant amount of support from the local community through fundraising and donations. However, in 1993, for the first time the Federal government identified the needs and concerns of people with HIV/AIDS as a priority (as quoted in the *BCPWA News*):

> An important goal of Phase II of the Strategy is to enhance the ability of persons living with HIV disease and AIDS to cope with their illness; to delay the onset of symptoms through healthy lifestyle choices; and to improve their access to services, treatment, care and support so that they are not excluded from society because of their physical, social or economic circumstances.

As Brown (1996) has noted, this shift in government policy meant that the BCPWA Society received more funding to develop health promotion programs for people with HIV/AIDS. Co-ordinating the expansion and development of programs and services meant that the Society had to become more formalized, strategic, and efficient. In Brown's (1997:111) words "the society has had no choice but to bureaucratize."

Some members of the organization have had concerns about this turn toward a more institutional approach and professional model of service delivery. As indicated in this letter to the editor published in September, 1995 in the Society's newsletter, there were concerns about the lost of PWA self representation as a result of partnerships with mainstream service organizations:

> The PWA Society is the only voice we HIV+'s have. AIDS service organizations generally exist for all people within the province, in that they exist mainly to prevent AIDS within the general population. The assistance we may receive from the ASOs while being appreciated does not constitute representation. We HIV+s must continue to speak for ourselves, collectively.

Frustrations have also been directed at the emphasis placed on administrative concerns over

the concerns of those infected by HIV/AIDS as the Society becomes less of a grassroots

organization, as expressed by one member writing for the newsletter in 1996:

> When I left Vancouver I was feeling tired, burnt-out and disillusioned. AIDS
> organizations in Vancouver, in my view, were becoming corporate minded and
> indifferent to the very people they were created to help. The organizations' continual
> struggles for money from both the government and the community was distracting
> attention away from the real concern, the welfare of people living with HIV and
> AIDS.

In response to the organization's growth, and to the concerns of members, the Society

initiated a strategic plan called "Toward 2000" in order to help the organization make the

transition to a more elaborate, hierarchical organizational structure, without, ideally,

sacrificing PWA self representation and self empowerment as priorities.

Establishing ties with different potential funding sources has also been a strategy used by

Body Positive in an attempt to manage the need to expand and develop programs and

services. [27] Since 1994, Body Positive has received support from different levels of

government for providing outreach services (arguably under the guise of AIDS prevention

more than support and education for those living with HIV/AIDS). In 1996, the editor of the

magazine wrote:

> In New York we look forward to continuing working with New York City
> Department of Health and the NYC Institute which enables Body Positive to
> continue providing community outreach, support services and education - for the
> first time in Staten Island.

AIDS organizations in the United States tend not to have the same working relationships with

government that has evolved in places like Canada or some European countries (Bayer &

Kirp, 1992). Instead, government funding is much more tenuous and conditional. For Body

Positive this means that they cannot rely on government funds as their main or sole source of support. This rationale has been used to justify seeking out and receiving support from corporations and the private sector for the development and continuation of programs and services. In 1997, the director of publications at Body Positive expressed this situation in an editorial in praise of David LaGreca, former Chair of the Board of Directors:

> As we move through our tenth year it is clear that Body Positive needs to grow and expand its services. [In the past few years] as government funding shifted to direct services it was crucial that Body Positive develop new sources of revenue. Throughout his involvement with Body Positive David has helped make it a priority to diversify our funding and bring Body Positive to the attention of corporate and foundation funders.

Receiving support from foundations and corporate funders is not foreign to Body Positive. In fact, the first source of revenue for the organization was from an AIDS foundation. Currently, however, as Clarke suggests, establishing ties with AIDS industries has become much more of a priority within the organization.

The professionalization of Body Positive over the past four or five years, as the organization has expanded and established institutional partnerships, has been an ongoing concern for staff, volunteers, and clients. For instance, writing in 1991, Michael Slocum noted, generally, that

> Body Positive has been transformed into an organization that is truly facing the range of HIV disease. Support groups are now dealing with issues like Karposi Sarcoma lesions and disease progression among their members. Simultaneously, HIV/AIDS organizations are becoming (or have become) more institutionalized. .... It occurs to me that our community-based organizations are now working now more for their own survival than for the people they exist to serve. The HIV/PWA self-empowerment movement no longer seems to exist. It is time for someone to rip open their shirt again and scream, "THIS IS WHAT AIDS IS ALL ABOUT."

Slocum's fear is that as organizations like Body Positive become more professional, in trying

to deal with "the range of HIV disease," they will lose a sense of urgency and activism and

become less responsive to those communities most in need of education and support. Later,

in 1995, the executive director of Body Positive, Frank Carbone, wrote,

> there is a list of things that I wish I could have accomplished. I'm sure my board, staff, and perhaps you as a client or dreamer wish I had done more as well. However, I hope I professionalized the organization enough so that it will be able to do part of all our lists in the near future. And while the organization is no longer 'grassroots' Body Positive retains the energy, beliefs, dedication and spirit of a grassroots organization.

Evident in Carbone's regret is the tension between the need to expand and formalize and the

dangers of becoming too professionalized.

Body Positive, like the BCPWA Society, initiated a strategic planning process in 1996 to

grapple with this issue. In 1997, when this was completed, the executive director, Linda Mayo

wrote that,

> we must continue to respond to urgent needs, reinvent and increase services, and fight for fewer and fewer resources. Moreover, Body Positive (along with other grassroots organizations) struggles with the aches and pains of becoming 'institutionalized' within governmental and corporate bureaucracies. Having faced these critical issues ... Body Positive has rededicated itself to remain true to its original mission and founding principles.

The organization continues to face such issues, in particular, regarding how to develop an

efficient model of service delivery that will allow them to reach increasingly diverse

communities infected and affected by HIV/AIDS without alienating those communities, gay

men primarily, that have historically provided the foundation for Body Positive as a grassroots

organization.

In sum, based on recent developments at Body Positive and the BCPWA Society, it is evident that PWA organizations have not embraced institutionalization or professionalism but instead are trying to grapple with this trend as both potentially beneficial and detrimental. According to Staggenborg (1988), social movement organizations that have been successful in managing the problem of expansion were able to combine elements of a centralised bureaucratic structure with elements of a decentralised and participatory structure. It would appear that PWA organizations like Body Positive and the BCPWA Society are currently working toward this more balanced approach to the problems of professionalization.

Transformation in PWA organizing since 1994 has had a direct impact on newsletters (and print media by and for people living with HIV/AIDS generally). Many have adopted aspects of mainstream magazines particularly regarding economic and practical concerns. However, this move toward a more 'professional' publication has been balanced by continued efforts to maintain and improve upon the use of print media as a means of self empowerment and self representation by those infected and affected by HIV/AIDS.

The restructuring that occurred at the BCPWA Society included the area of communications. The strategic plan announced in 1995 identified as priorities the following two objectives regarding communication and education: "to ensure that we maintain a positive and dynamic image in the community" and "to produce and deliver educational resources that will empower those living with HIV and inform those who are affected." Following this announcement, a new staff position was created - Director of Advocacy and Communication - in order to develop forms of community outreach that were consistent with the broader changes occurring within the organization. The objective was to work towards

making the agency's publications cost effective, better quality, and more effective in reaching

the organization stakeholders - clients, funding agencies, community partners, and, at some

level, the general public.

This new approach to communication had a direct impact on the *Vancouver PWA*

Newsletter. One of the responsibilities of the new director of advocacy and communications

was to work with volunteers in giving the newsletter a make-over. The new staff member,

Peirre Beaulne, had previously worked in mainstream media production and brought this

knowledge to bear on the revisions that were made to the newsletter. In broad terms, changes

were designed to make the newsletter read and look more like a magazine (though it was still

evident that it was the product of a community-based organization rather than a publishing

house). Initially, this involved a simple name change - to the *BCPWA News* - reflecting the

extended mandate of the organization. However, eventually, more significant revisions in this

same spirit were made to the production, format, and content of the newsletter.

In terms of production, the most significant change was that the newsletter was no longer

printed using the organization's computers and photocopiers. Much to the surprise of many

of those involved in the publications at the time, using a printing company was more cost

effective than using resources designated for the organization's operation (like paper, the

photocopier, and computers). Eventually, in 1997, the decision was made to centralize all of

the organization's print media:

> all of the BCPWA publications will be published in a similar format, using the
> services of one design/printing company, which (as you might have guessed) is
> intended to take some of the strain off of the publications' budget.

Using a printing company also improved the overall appearance of the publication (for example, the paper and the graphic design were of better quality) and it helped to ensure that it would be produced and distributed on a more reliable and consistent basis.

Other changes were made to make the newsletter more cost effective. Consistent with the general turn toward a magazine format, the newsletter began to offer subscriptions asking readers to make a donation to the BCPWA Society in exchange for receiving the publication. In addition, local organizations and institutions involved in AIDS research were invited to use the newsletter, for a fee, as a means of reaching HIV infected and affected individuals. Researchers could publish announcements or include surveys in issues that would be distributed to the 3600 organization members across the province. The rationale for introducing fundraising aspects into the newsletter was to offset the costs of revisions and in time make the publication self sufficient.

The production process was revised by eliminating several stages in the way that the publication had been printed. For instance, a more clearly defined division of labour was established. An editorial committee, consisting only of people with HIV/AIDS, was formed to deal exclusively with planning upcoming issues, generating ideas, and editing copy before it was published. Members with an interest in writing, photography, or research were encouraged to volunteer for the publication in that capacity - occasionally they might even be compensated for their efforts. Other volunteers, not necessarily HIV infected, were responsible for the more mundane aspects of producing the publications, like mailing and general distribution. The latest development has been the formation of a group dedicated to building and producing a webpage version of the newsletter.

Revisions were also made to the newsletter's content and format. Elements of the publication directly relating to the organization - those associated with a conventional agency newsletter - were lifted from the body of the publication and placed together in a separate insert called, *Positively Happening: Your Guide to Just About Everything*. The following three features were added to the newsletter: (1) an editorial (written by the editor or by a member of the organization); (2) several regular columns consisting of practical information (treatment and advocacy updates in each issue) and contributions from writers, artists, activists (recently there was a summer fiction issue, for instance); (3) one or two feature articles - 'cover stories' - done by a local writer/journalist or reprinted from another PWA or gay print media (for instance, a three part article entitled "The Cost of AIDS" was reprinted from a local gay publication).

There have been changes in the content of the newsletter. In general, less emphasis has been placed on issues specific to Vancouver because the publication has had to also appeal to readers across British Columbia, and North America, as well as those living in Vancouver. More specifically, greater emphasis has been placed on the publication being an information resource for people infected or affected by HIV/AIDS. For instance, more space has been devoted to treatment updates and a news service was hired to compile articles and new stories about HIV/AIDS - a selection of these are published in a "News and Notes" section. Personal accounts of living with HIV/AIDS, mostly by local members and often offering advice, have also been encouraged under the newsletter's new format.

In contrast to what might be expected given the organization's reliance on external funding, the content of the newsletter has not become less political. Articles and opinion

pieces have continued to be critical of government policies and inaction without fear of having

government support withdrawn. Editorial changes in this respect have occurred only in terms

of giving a positive impression of the internal state of the organization and its membership.

In previous years, several members of the Society felt frustrated with the professionalizing

changes occurring in the organization. In many cases the newsletter was used as a forum for

this discord. For instance, one regular contributor and prominent member consistently

criticized the organization in his columns: "as the AIDS epidemic grew, so did our

membership. The simple idea of PWAs running their own Society to support other PWAs got

buried in the bureaucratic jungle, and the idea that I could actually do something for other

members got lost with it." Gradually, though, giving voice to internal political debate was

replaced by material dedicated to providing a forum for education and support - information

that would help people infected and affected make informed decisions about improving their

health and quality of life.

Changes made to the *BCPWA News* - its transformation into a more professional looking

and feeling publication - were made not just to keep pace with developments in the

organization but also to empower those people with HIV/AIDS who produced or read the

publication. There have been advantages and disadvantages to this approach. For instance,

revisions to the production process were intended to make the involvement of volunteers

more meaningful - those involved spent more time in creative pursuits rather than spending

hours tending to the photocopier or stuffing envelopes. At the same time, though, the

credentials needed to 'qualify' to work on the newsletter have inflated. The following, written

in 1998, are examples of recent calls for volunteering opportunities with the newsletter:

Treatment Information Program News, Managing Editor: must have experience with newsletter production including editing, proofreading, and computer skills. This person will ensure a professional and timely product. The BCPWA Webteam: You must have a good knowledge of web-page construction and HTML coding. Team members must be dedicated and commit to strict deadlines.

It is arguable that many people with HIV/AIDS would not come to the organization with these skills - especially given that the disease appears to be most prevalent among disenfranchised communities. In this sense, instead of stressing participation, the publication has adopted an approach that attempts to identify those people with HIV/AIDS who are particularly qualified, with a particular professional attitude, to create material that can be read and used by the broader HIV community.

In sum, the general tone of the BCPWA News in recent years has become less casual, intimate and focused on organizational issues. Instead, changes have been initiated that have made the publication more useful, formal, and public (in the sense of being generalized). A greater priority has been placed on producing a publication that reflects the Society's status as a formal and efficient AIDS service organization (as opposed to a internally divisive grassroots PWA coalition). To accomplish this, the publication has incorporated aspects of the mainstream media and even scientific or medical media (i.e., medical journals) while still trying to maintain, and even enhance, its commitment to PWA self empowerment and self representation.

Similar to the BCPWA News, in 1993, actions were taken to revise Body Positive in accordance with broader changes in its parent organization. At this time, Body Positive began restructuring in response to increased government funding. There was a perceived need to

make the delivery of services and the overall operation of the organization more professional.

As one respondent, involved in the magazine at the time, explained,

> the organization was professionalizing - that was the plan - that the organization behave in a more professional manner. We never really had funding for the magazine. However, we had just received funding from the City of New York; they were very generous and flexible in terms of how we used the money. We now had to be more careful about the quality of the magazine - which was a good thing - but in ways that we did not have to in the past.

Like the other programs offered by Body Positive, the magazine needed to become more professional - a better quality publication - without, at the same time, sacrificing its objective as a vehicle for PWA self empowerment and self representation.

At this time the magazine did not have a managing editor. The entire staff, under the guidance of Jeffery Karaban, collectively acted as editor when Jim Lewis became too ill to work on the magazine. The decision regarding who would take over the position of editor was strategically important: this person had to have knowledge of the mainstream print media and of HIV/AIDS. In the summer of 1993, Jeffery Schaire became editor and subsequently began to make revisions to *Body Positive*:

> Jeffery came to Body Positive after serving as editor-in-chief of *Art & Antiques*. Although his editorship was brief, his impact was felt with his first issue, August 1993. As part of a comprehensive redesign, he introduced a number of new sections, like News and Notes, as well as a new cover and logo. He reaffirmed our commitment to giving both a voice and a face to the diverse community that is affected and infected by HIV. He was passionate about the magazine as a source of information, a platform for diverse opinions, a place where you might find a little inspiration, a little hope, some anger, some humour and maybe even a date.

As is suggested in this obituary published in *Body Positive* (Schaire died of AIDS-related illness, October 30, 1995), the new editor was well suited to the task of revising *Body*

Positive. In less than a year he had used his experiences as a person with HIV and his involvement with *Art & Antiques* to remake and update the publication.

Redesigning *Body Positive* primarily involved changes to the format and content. Apart from the introduction of new software and computer technology little changed in the production of the magazine. Staff members coordinated the work of volunteers and contributors to the magazine. As mentioned, new sections were added to the format. But in addition to this, the magazine's internal organization was streamlined and shortened so it resembled that of a conventional magazine: in each issue there were several regular columns or "Departments" and two or three feature cover stories. The newsletter component of the publication was truncated. Announcements and advertisements were kept, but commentary about the organization was, for the most part, either absent, or limited to a single section at the beginning of the magazine to be used only when necessary, for instance, when members needed to be informed about developments in the organization (eventually this would become a standard section of the magazine).

Schaire also added a different tone to the publication. First, more emphasis was placed on general topics of interest relating to HIV/AIDS. And second, more photographs, graphics, and selections from popular culture were used to accentuate articles or profiles. Large photographs of positive and seemingly interesting personalities from the HIV community dominated the cover of each issue. As one respondent noted, "he gave it a lot more attitude, a lot more personality - he classed it up and made it look more snazzy. It had less of the grassroots showing than before."

Two prominent and identifiable changes occurred at this time in the magazine's content. More energy and space was devoted to highlighting news and stories about HIV/AIDS and AIDS - what is now referred to as AIDS journalism. This was fostered by the involvement of professional writers and journalists who began contributing pieces or helping with stories and articles. Again, Schaire's obituary noted that, "perhaps one of his most lasting contributions was to bring to the *Body Positive* the work of artists, writers, and friends he had known through his years in publishing." In addition to established writers, it has been interesting to see over the last four years a growing number of people with HIV/AIDS who have decided to become freelance writers and have begun their work by contributing to PWA print media. In fact, currently in the United States there are several funds that have been established to help support aspiring writers with HIV/AIDS.

This move toward AIDS journalism did not mean that less attention was devoted to providing education and support by and for those infected and affected by HIV/AIDS. In fact, this was another area that Shaire identified as a priority in revising the magazine. Members of the HIV/AIDS community were more actively encouraged to share their experiences and knowledge of living with the disease. Staff were actively involved in planning and shaping the material to be included in each issue, especially regarding education. This renewed commitment to the magazine brought new features, like "Ask Nurse Thrush," which invited readers to ask questions to an anonymous, and particularly campy, health professional who offered reliable, sensible, and practical advice not just about medical concerns but on all aspects of living with HIV/AIDS. In terms of support, volunteers and clients of the

organizations were encouraged to write about their experiences. Those who were not comfortable writing were interviewed and profiled by a staff member or a volunteer.

The revisions made during this period have become trademarks of the magazine. Apart from minor changes as the magazine grew in size and scope, subsequent editors have kept the same general format and tone that was established in 1993 and 1994. Although it is evident that Shaire played a key role in the development of *Body Positive*, it would be a mistake to attribute too much to one person. There were organizational forces that contributed to the changes that were made by Shaire at this time. As one respondent has noted,

> there was a lot concern, primarily among members of the Board, that we were too political - and that that would give a bad impression. Body Positive is funded through the government and the magazine is an emblem of who we are as an organization. It was seen to be presumptuous for us to take a high moral tone based on a leftist agenda. And that was really depressing: we were very cosy thinking and feeling that way. But when it came down to it, we also did not want to alienate, say, a Republican reader.

Professionalizing meant that *Body Positive* had to become a magazine that focused entirely on the politics of individual self-empowerment. That is not to say that other levels of political debate were entirely censored. For instance, if a person with HIV/AIDS wrote about government inaction it would be published in the magazine. However, political debate was not considered to be a priority for the organization. Instead, priority was placed on creating an appealing, quality lifestyles magazine by and for the HIV/AIDS community - a publication that reflected Body Positive's status as a self help organization.

In recent years the status of *Body Positive* as a viable publication has been questioned on several fronts. Funding from the state has become less "flexible and generous" as direct support and education services have become a priority (a magazine distributed around the city

to communities most affected by HIV/AIDS is considered to be an indirect service). In addition, it appears that fewer gay men are reading and subscribing to the magazine. There are several theories as to why this might be the case. At an organizational level, more resources have been directed at providing community outreach to heterosexual women, people of colour, injection drug users, and prisoners. This has left some members of the gay community feeling as if they have been passed over by Body Positive - an organization that has been central to and primarily supported by gay and lesbian communities in New York City. In addition to this, the popularity of relatively new (for profit) magazines about HIV/AIDS, like *POZ* and *Art & Understanding*, has, for the first time, introduced a measure of competition between PWA print media. It is thought that many gay readers are turning to publications like *POZ* in part because they are tailored, albeit subtly, to a more affluent gay audience. Since its inception, *Body Positive* has relied primarily on support and donations from its readership. The prospect of alienating their gay readership and having them turn to other publications means that *Body Positive* would lose a considerable amount of support from the HIV/AIDS community. The recently published special pride issue can be read as an attempt by the magazine to reconnect to gay and lesbian communities in New York: "A time for reuniting. It's that time again for lesbians, gays, bisexuals, and transgendered people to reunite in support of each other as diverse people representing one community - to parade our pride down the avenues, and to re-establish the important ties that bind us all."

There have been several actions taken in response to the prospect of fewer and less secure resources for the magazine. For instance, those involved have had to do more with less and, for the first time the magazine has become smaller in terms of its size and the number of

people involved. More significantly, though, *Body Positive* has started to accept advertising revenue from AIDS industries. Despite objections from some people in the organization, it was decided that receiving funds from drug companies like Merck was necessary in order to sustain the quality and tone of the magazine. The current editor is adamant that this use of corporate funding has not compromised the publication's commitment to serving and empowering those infected and affected by HIV/AIDS. It is, however, a sign of the extent to which the AIDS movement has become reliant, particularly in the United States, on funding from the private sector rather than the state. *Body Positive* is currently about to change editors once again. It will be interesting to see what developments this change in leadership brings as the organization and the magazine continue to deal with issues regarding professionalization and the increasingly questionable funding sources for community-based AIDS organizations in the United States.

In sum, like AIDS organizations, print media by and for people with HIV/AIDS have struggled with the pressure to become more professional. Elements of the mainstream print media have been adopted in an attempt to produce a better quality, more respectable, and more appealing publication. At the same time, print media have also tried to renew their commitment to being a forum and as a resource for people infected and affected by HIV/AIDS. In some respects these revisions have been successful: print media like *Body Positive* and *BCPWA News* have succeeded in moving beyond being grassroots publications. However, there has been an accompanying escalation in the implicit and explicit credentials required to participate "effectively" in creating a "quality" publication by and for people with HIV/AIDS. In other words, in many cases, the production of information has become less

collective and more specialized. As a result, participation by those infected with HIV/AIDS has been limited to reading rather than producing publications like *Body Positive* and *BCPWA News*.

Conclusion

In this chapter I have tried to tell several overlapping stories about AIDS organizing and the formation and evolution of print media by and for people with HIV/AIDS. First, on a broad level, there is the historical development of the PWA movement, examining how those living with HIV/AIDS have collectively responded to the AIDS crisis in North America. Following these trends in the PWA movement, the second story is about the gradual professionalization of PWA organizations, from grassroots collectives to formalized and bureaucratic agencies, in response to increased institutional support and the growing needs of those infected and affected by HIV/AIDS. And last is the story of the print media that have been produced within the context of this community-based response to HIV/AIDS: how they have been influenced by transformations in the PWA movement and PWA service organizations. In each case it is clear that organizing by people with HIV/AIDS has played a key role in the community-based response to HIV/AIDS and should not be forgotten or passed over as the AIDS movement continues to provide education, support, and advocacy to those infected and affected by HIV/AIDS. It is also clear that PWA organization newsletters, as a type of media activism, have contributed to the construction of an alternative public sphere for people living with HIV/AIDS. One of the key lessons to be gained from this chapter is that studies of alternative media need to take into account their relationship to and

reliance on, particularly in terms of the allocation of resources, contemporary social movements.

Based on this analysis, it is possible to make several concluding remarks regarding the two questions that have shaped this chapter. First, how have changes in the PWA movement and PWA media had an impact on the construction of an alternative public sphere for people with HIV/AIDS? In looking back over the past fifteen years, it has been instructive to see the extent to which publications like *Body Positive* and *BCPWA News* have been tied to the PWA movement and to the community-based response to HIV/AIDS. It is through this connection that the agency newsletters can be seen as examples of how contemporary social movements construct alternative public spheres for marginalized or oppressed communities.

Broadly speaking, it would appear that this public sphere for people with HIV/AIDS has become less concerned with encouraging and supporting localized forms of political organizing and activism among people with HIV/AIDS; instead, greater priority has been placed on creating a supportive and instructive environment for a broad and diverse community of people infected and affected by HIV/AIDS. Also, participation in this public sphere has shifted as well. Initially, there were few barriers for those people with HIV/AIDS who were interested in becoming involved in grassroots media projects. However, as media projects have become more formal and professional in their approach, it has become harder for people with HIV/AIDS to be involved in forms of self representation unless they already have specific and often specialized skills related to publishing or journalism. Broader participation, as is the case with the mainstream media, has taken the form of consumption

rather than production as readers are expected to treat publications as a source of practical information rather than an expression of their identities as people living with HIV/AIDS.

Such transformations in PWA media, and in an alternative public sphere for people with HIV/AIDS, has come in response to pressures from the AIDS crisis itself, but also, from an increasing institutional investment in people living with HIV/AIDS and in the community-based response to HIV/AIDS. These changes suggest that print media by and for people with HIV/AIDS have become less overtly political (in the same way that there is often a distinction made between feminist media and media by and for women) though they are still products of the community-based AIDS movement.

The second question that remains is why newsletters have survived and thrived when, in general, so many alternative media projects fail. It is evident from these two cases that there are several factors at play. Prominent among these factors are strong ties to an organizational infrastructure and the commitment and vision of those who took ownership over these projects as valuable and important contributions to the community-based response to HIV/AIDS.

The growth in scope and severity of the AIDS epidemic provided a definite need for education and support for those infected and affected and a critical mass of people interested and willing to become involved in the movement and in media projects, particularly once those infected began living longer once diagnosed and the disease became increasingly recognized as a chronic rather than terminal condition. However, what has been a source of strength for publications like *Body Positive* and *BCPWA News* is their ties to community-based PWA organizations. Body Positive, New York and the BCPWA Society have provided

the resources - not just in terms of funding but also volunteers, equipment, and social networks - and the stability needed for print media projects to sustain themselves and, indeed, reach well beyond the confines of their parent organizations. Also, since each publication began with their parent organization, over time they became entrenched in the increasing formalization of the BCPWA Society and Body Positive. As result, the *BCPWA News* and *Body Positive* were integrated into organizational changes rather than abandoned.

In addition to organizational factors, it is evident that key individuals have also played a role in the development of *Body Positive* and the *BCPWA News*. In particular, the publications have benefitted from the involvement of people with HIV/AIDS who brought skills and knowledge from the mainstream publishing industry. It was also evident that many people were extremely committed to the continuation and advancement of the two publications. Several of the staff and volunteers at the BCPWA Society, for instance, spoke of the sense of pride and meaning that is derived from being involved in producing a publication.

In closing, it is interesting to speculate on what might lie ahead for print media like the *BCPWA News* and *Body Positive*. The emergence of new media technologies, like the Internet, and the growing use of existing technologies like the telephone and the fax, have raised questions about the efficacy of print media as a forum for people with HIV/AIDS. In years to come, especially as government support for AIDS organizing decreases, more energy may be devoted to providing direct education and support services as a more effective means of community outreach rather than relying on the production of print media. Most significant, though, is the issue of continued professionalization. While AIDS organizations continue to

rely on dominant institutions, particularly the corporate sector, the disease is spreading at an alarming rate among those communities most disenfranchised in North America (and internationally). Such ties may make it difficult for organization to remain accountable to those most in need of programs and services. For those involved at *POZ* magazine, this turn toward private industries is a positive shift. It represents an new kind of AIDS activism that does not particularly care who funds the community-based response to HIV/AIDS. They are confident that these 'partnerships' will not influenced or 'taint' their commitment to the needs and concerns of those infected and affected by HIV/AIDS. Others involved in AIDS organizing are less enthused by the extent to which publications like *POZ* and *Body Positive* have begun to embrace the involvement of dominant institutions in their work. They believe that AIDS organizing and AIDS activism is about, at some level, making public institutions accountable to the needs and interests of all publics - including the diversity of those infected and affected by HIV/AIDS.

It is true that the actions of many industries are motivated solely by capital. The corporate sector is committed to profit, to the interests of share holders, and to remaining competitive in a global economy. It is not primarily concerned with addressing the needs of people with HIV/AIDS. Reliance on the corporate sector means that the public sector, to a greater or lesser extent, may feel less responsible for supporting and contributing to the fight against HIV/AIDS. It also gives credence to a vision of society that has industry and the economy as its central institution; under this arrangement, when a crisis arises like HIV/AIDS it is the private sector that is expected to respond rather than government. The counter argument, articulated by those at *POZ*, though, is that activists must work at making both the private

and public sector accountable in the case of a widespread epidemic. In the age of promising

new treatments and faltering state support for HIV/AIDS it is difficult to know whether or

not a renewed activism will emerge among people with HIV/AIDS - like there was in 1983

and 1989- directed at advocating for those most directly affected by the disease.

FOOTNOTES

1. The first agency newsletter, and PWA media, is *Newslines*. It began when a group of people with AIDS formed the PWA Coalition of New York. This publication helped to popularize newsletters as a forum for those involved in PWA organizing. It gained further notoriety when it was developed into the anthology, *Surviving and Thriving with AIDS*, published in 1987.

2. The four periods that I have described are intended to describe broad and overlapping trends within the PWA movement; they are analytical tools not real stages or meant to signify rigid divisions in the history of organizing by and for people living with HIV/AIDS.

3. In conducting this analysis I have relied on two sources. The content of the publications themselves combined with accounts from those involved in their production is my primary source of data. They provide a firsthand perspective on how changes in the AIDS movement have impacted print media projects. Unfortunately, information about the early history of publishing by and for people with HIV/AIDS is sketchy. The early issues are less than ideally self-reflective. And, it is difficult to find people who were involved in the early publications during their initial years of production. Nonetheless, the back issues and personal accounts provide insight into developments in print media over the course of the AIDS movement. It would be difficult to conduct this analysis using information exclusively from or about print media by and for people with HIV/AIDS. There simply is not enough information or analysis about the AIDS movement. To compensate, I have turned to studies of the community-based response to HIV/AIDS as my second source of information. I have used this research as a means of identifying the dominant themes and trends that have occurred within the community-based AIDS movement.

4. It is beyond the scope of this project to examine the contributions of an established gay press in the development of the PWA movement and the AIDS movement. This would be a valuable area for future research.

5. AIDS media projects did not replace the coverage of HIV/AIDS in the gay media; instead, the two exist as parallel media, each with a distinct, though often overlapping purpose and perspective. Of the people I interviewed many were involved in gay media projects. This experience meant that they brought valuable connections and skills to PWA media projects. This issue would be an interesting study to conduct. As social movement media, they share a similar history and have influenced each other over the past fifteen years. The interactions between social movement cultures is an area that has received little attention. For instance, in terms of the prehistory of AIDS media, it is curious that organizing by and for people with HIV/AIDS in Toronto did not produce a publication similar to the *BCPWA News*. There is some speculation that publications like *The Body Politic* and *Rites* met the communication needs of those HIV infected. This is an interesting question in terms of the inter-relationship

between gay and lesbian organizing and the grassroots AIDS movement, or more specifically, organizing by and for people with HIV/AIDS.

6. The influence of gay media on PWA media did not end with the development of newsletters. It has endured. The two genres have mutually informed each other and continue to do so. Exploring this topic would be an interesting area for further research.

7. Initially, continuity posed an ongoing challenge for grassroots PWA organizations. Even in large urban centres it was difficult at times to maintain a critical mass of staff and volunteers needed to run services and programs. Gradually with the support of AIDS service organizations and as membership increased, PWA organizations matured into viable and autonomous entities within the community-based AIDS movement.

8. The name of the BCPWA Society has changed several times. It began as the Vancouver Persons with AIDS Coalition. This became the Vancouver Persons with AIDS Society. And most recently, the name of the organization is the British Columbia Persons with AIDS Society, or the BCPWA Society. When possible I have tried to incorporate the name change into the history of the organization, and its newsletter, as it reflects the development of the BCPWA Society over the years, rather than use one title throughout. However, the different references to the same organizations may, understandably, create some confusion.

9. It was important at this time that the Coalition not be perceived as a gay organization, but, at the same time, acknowledge that its members were almost exclusively gay men and that AIDS organizing is indebted to gay liberation politics and the resources within the organized gay and lesbian community. This tension can be seen in the following announcement of the agency's involvement in Vancouver's Gay Pride celebration: "The 1987 Gay Pride Parade: Although the PWA Coalition exists to reach out to all Persons with AIDS/ARC, often we are dismissed as a 'gay' organization. Labels or not, the gay community has been the hardest hit, and has responded with the strongest support. It is with pride that we show our support and join in this years Gay Pride Parade ... ." A similar relationship existed between the Vancouver PWA Coalition and AIDS Vancouver (an AIDS service organization). In clarifying this association, two founders of the organization wrote: "Often there has been confusion about the relationship between the Coalition and AIDS Vancouver. While we are two distinct entities, we share similar goals and objectives. We have an excellent working relationship and compliment each other in dealing with the AIDS crisis in the province. AIDS Vancouver is primarily a service provider. The Coalition is a group of PWA/PWARC's working together to help ourselves. As a collective it is never them and us. It is just US!"

10. Based on conversations with staff and volunteers, there appears to have been a debate within Body Positive about the extent to which organizations should focus exclusively on HIV virus and the wide spectrum of HIV and AIDS. In terms of direction, the board made a decision to keep focusing on those who were newly diagnosed as HIV positive, but also

provide education and support services for people with an AIDS diagnosis. This decision was made in part because those in the HIV/AIDS community realized more fully that there was not a linear progression from HIV infection to AIDS.

11. It was evident that, as a publication, the newsletter was informed by a heritage of publishing by gay and lesbian communities - locally, by gay and lesbian media institutions like *Angles* and Little Sisters Bookstore and, nationally, by publications like *The Body Politic* and *Rites* (based in Toronto, but with a national readership). Also, the substance of the newsletter was grounded in the experiences of politically conscious gay men with AIDS. Writers spoke openly about their lives as gay men, not just as people with HIV/AIDS. Topics of sexuality and a sex-positive approach to living with HIV/AIDS were priorities. As well, the resource listings and local advertisement were situated in the local gay community. As Brown and Gray stated in August of 1987: "A person's sexuality should never enter into their fight for survival, and we must remain a safe place for anyone who may find themselves so diagnosed to come."

12. The entire list of demands provides a interesting glimpse into the state of the PWA movement in the late 1980s and early 1990s: (1) HIV must be treated as a chronic and manageable disease and access to treatments is a social and moral obligation; (2) HIV must not be treated as highly infectious; (3) a code of rights must preserve the humanity of people with HIV/AIDS; (4) a multi-national data base for treatment information must be created; (5) placebo trials must be recognized as unethical; (6) a standardized criteria for drug approval must be created; (7) international education programs about preventing HIV transmission must be initiated; (8) it must be recognized that women have a right to control their bodies and that gender inequality affects women's access to information about HIV transmission; (9) industrialized nations need to establish a fund to assist poor and developing countries; (10) poverty must be recognized as a co-factor in HIV disease.

13. In Vancouver, as Brown (1997) has noted, advocacy was taken up largely by AIDS service organizations rather than by direct action groups. Gradually, this advocacy led to greater government support for (and involvement in) the Vancouver PWA Coalition.

14. Between 1986 and 1989 the amount that the Coalition received from government increased substantially; although many of the services that were provided at the time, like complementary therapies, continued to be funded exclusively through donations and fundraising. In 1987 the Coalition received its first funding from the Health Promotions Branch of the Federal government ($27,000 for administration and the salary of one staff member). As was reported in the *BCPWA News*, "this is the first time a Coalition of people with AIDS has ever been funded by the Federal Government. Once again, we are proud that we have led the way!" A year later, in spite of pressure from government to amalgamate the PWA Coalition and AIDS Vancouver, the organization received its core funding from the City of Vancouver ($11, 750 per year for a second staff member and administration).

15. As Brown (1996) has noted, while the Women's AIDS Network formed at this time in Vancouver, the PWA Society tried to address all the needs and concerns of people with HIV/AIDS - education, support, and advocacy. In other major urban centres, in Canada, notably Toronto, and the United States it was more common that specialized organizations would work together in meeting the needs of those infected and affected by HIV/AIDS - for example, in Toronto, AIDS ACTION NOW! focused on advocacy, the Community AIDS Treatment Information Exchange (CATIE) provided education in regards to health care options, and the PWA Foundation of Toronto provided practical education and support services.

16. PWA media during this period of time, in general, grew in scope and type. New organizations began to produce their own newsletters about HIV/AIDS. Much of the growth in publishing, though, came in the area of treatment information. Most publications began to offer regular and systematic information about developments in medications, clinical trials, delays in the approval of drugs, and so on. As suggested in the fifth demand set out in the Montreal Manifesto, AIDS organizers began to place greater priority on developing means by which people with HIV/AIDS could have access to comprehensive and understandable information that would help them make informed decisions about their health care. This material was shared primarily through print media. As a result, treatment publications emerged during this expansion period as the predominant type of print media by and for people with HIV/AIDS. Information about treatments was published in several different ways, ranging from small, locally produced updates and tabloids to much broader international periodicals resembling medical journals. The type of information was largely about developments in Western scientific medicine. However, there were also a few publications about health care alternatives to allopathic medicine. In general, treatment information projects were about helping people with HIV/AIDS take more control over their health care by being informed about their options. Establishing programs that provide treatment information was a victory for AIDS activism because it was a sign that the AIDS establishment was beginning to acknowledge the needs and interests of people living with HIV/AIDS. The relationship between PWA media and treatment activism is taken up in more detail in the next chapter.

17. In recent years, the organization has tried to deal with this problem of consistency by having the editorship done by a committee of people living with HIV/AIDS. This committee was also introduced as the workload for the editors expanded.

18. Another factor contributing to this problem of consistency was that the *Vancouver PWA Newsletter* was almost entirely the responsibility of volunteers. A staff member was assigned to oversee the production, but their position was often not closely linked to communications within the organization. As a result there was often a constant demand for volunteers to work on some aspects of the publication.

19. Several people that I interviewed mentioned that often involvement in the agency newsletter was seen to be a stepping stone to other more prominent volunteer positions like the speaker's bureau. This meant that before the newsletter developed a higher profile it is likely that many of those involved soon moved on to other activities in the organization.

20. On other levels, the newsletter was also used during this period as a means of linking the PWA Society with AIDS organizations in Canada, the United States, and internationally. Organizations in different parts of the world that consider themselves part of the community-based AIDS movement stayed informed by exchanging their publications. Several of those people involved in the publication have argued that this exchange has significantly raised the profile of the Vancouver PWA Society within the AIDS movement internationally.

21. This description of the two primary roles of the publication - newsletter and magazine - may give a false impression about how the content was written and presented. In terms of advocacy, for instance, it would be common for a member of the advocacy committee to write a regular report on their activities that month (published as a newsletter). This report would serve as a springboard for an article on living with HIV/AIDS that dealt with advocacy, like how to handle discrimination or changes in legislation around disability (published as a magazine). In other words, in practice, the two aspects of the publication were in fact often closely inter-related.

22. It was evident in my conversations with people involved with Body Positive about the history of the magazine that editors have been the driving force behind changes in the publication. Our discussions would always revolve around the different editors and their similar and differing intentions in overseeing the magazine.

23. This has had advantages and disadvantages for organizing by and for people with HIV/AIDS. For instance, the PWA self empowerment movement is now only mentioned in the past tense, for the most part. At the same time, though, more than ever before, those infected with HIV are actively involved in positions of power within the AIDS movement.

24. There is also a considerable literature on the formalization of social movement organization in general (see Cain, 1993b).

25. This corporate involvement has come, to a large extent, as a result of advancements in treatments for HIV/AIDS. A new generation of drugs called protease inhibitors, used in combination with other AIDS medications, have been, in some cases, greatly successful in slowing the progression of HIV/AIDS - to the extent that they have been, when first introduced, inflatedly referred to as a potential cure. Pharmaceutical companies are the most common AIDS industry, although they are by no means alone in the commodification of HIV/AIDS. This process began on a large scale with companies purchasing the life insurance policies of people with HIV/AIDS. Since that time, a diverse range of companies have began to market their products (supplements, vitamins, vacations, bottled water, and so on) to the

HIV/AIDS community. Many of the newer products seem to be directed at health promotion rather than life insurance, reflecting the fact that people with HIV/AID are living longer and are interested in improving their health and their quality of life.

26. The role of the organization provincially seemed to be primarily providing a focal point in which to co-ordinate the network of community-based PWA groups that were emerging across British Columbia. Much of this move toward a broader mandate was facilitated by a partnership between the Vancouver group and the newer PWA group formed on Vancouver Island. Eventually, the network extended to other regions of the province.

27. In terms of partnerships with AIDS organizations, Body Positive has a history of receiving support from other AIDS organizations in New York like the Gay Men's Health Crisis and the PWA Coalition of New York. And, while Body Positive has not developed formal partnerships, there have been efforts to collaborate with mainstream organizations on, for instance, large scale fund raising events like the AIDS Walk in New York.

CHAPTER SIX: TREATMENT PUBLICATIONS

At the International AIDS Conference in Vancouver in 1996, news of a promising new treatment for AIDS, called protease inhibitors, was officially released. Evidence was presented suggesting that, when used in combination with other AIDS medications, the new drugs could potentially eradicate HIV from the body. When this news reached the media there were rumours of a possible cure. The *New York Times Magazine* reported that we may well be entering into the twilight of the epidemic. Unfortunately, combination therapy and protease inhibitors have not turned out to be the magic bullet they were touted to be in the media. People with HIV/AIDS have benefitted from the new medication. Many have also experienced devastating side effects. The long term health effects of these medications are still unclear. In other words taking the drugs may do more harm than not taking the drugs. As Mike Barr has noted, writing for *POZ*, "the protease inhibitors can harm as well as help people with HIV. Even while some researchers profess complete eradication of HIV, protease combos often fail those who need them the most. Rather than the twilight, we may simply be getting our first glimpse of a new morning in the struggle against this disease."

This roller coaster of optimism and pessimism regarding the treatment of HIV infection is not new to the epidemic. In fact, it has become a recurring theme. The introduction of AZT in the 1980s, for instance, brought similar hope. However, people with HIV/AIDS were given too large a dose, causing harmful side effects, and it turned out that the medication alone was

not an effective treatment for HIV/AIDS. Currently, the most recent trend is the use of a drug 'cocktail' - a combination of antiretrovirals, like AZT, and protease inhibitors. It is thought that using several different medications at the same time is a way of gaining the maximum benefit for the longest period of time. It would seem that over the course of the epidemic thus far, advancements in AIDS medications have brought about health benefits, but all have also created health problems, and none have lived up to their reported or anticipated potential.

Another key issue in regards to the treatment of HIV/AIDS has been accessing medications. Advances in medical science have created opportunities and hope that HIV/AIDS may be treatable; however, there have been considerable economic and political barriers to the use of treatments. For instance, one of the key criticisms of combination therapy is the cost of drugs. It is not uncommon for people with HIV/AIDS to spend thousands of dollars in AIDS medications. Such high costs, and the lack of political will, has meant that access is limited to those who have the necessary personal resources. Furthermore, it has meant that people with HIV/AIDS living in developing countries have, for the most part, been denied access to even the most basic AIDS medications.

It is not surprising, then, given this social and political climate in health care, that political organizing around the treatment of HIV infection (what has been called AIDS treatment activism) has been a central component of the community based response to HIV/AIDS (Ariss, 1996). Treatment activism among groups like ACT UP and AIDS ACTION NOW! have focused on influencing those power structures (government and pharmaceutical companies) in control of the development and approval of medications (Carter, 1992; Carter & Watney, 1989). On another level treatment activism can be extended to include the creation

of advocacy, support, and education programs for people living with HIV/AIDS. One of the key initiatives in this less evident and less explicit form of activism has been the development of forums through which people with HIV/AIDS can share information about treatments and health care generally. An important factor contributing to such efforts has been the lack of reliable and accessible information about health care for people with HIV/AIDS. As a result, those infected and affected by HIV/AIDS have had to create their own resources in terms of learning about what health care options are available.

This chapter examines how community-based media have been used by people with HIV/AIDS to produce and disseminate treatment information. In particular, I am concerned with the emergence and decline of print media as a forum for dialogue about health care and HIV infection. The purpose of this analysis is twofold. First, I look at how treatment activism, as a component of the AIDS movement, has constructed an alternative public sphere for people with HIV/AIDS about health care. Treatment publications are examined as an intermediary link in the changing use of different media in the construction of such public forums. Secondly, I am also concerned with how the idea of being 'community-based' has served as a foundation for such media projects by and for people with HIV/AIDS.

As case studies, I focus on two treatment publications located in Southern Ontario, Canada. *The Positive Side* is a publication of the Community AIDS Treatment Information Exchange, a treatment specific AIDS organization located in Toronto, Ontario. Between 1991 and 1995, *The Positive Side* was produced on a quarterly basis by a collective of people infected and affected by HIV/AIDS. *Treatment Information Flash* is a publication of the Hamilton AIDS Network, an AIDS service organization in Hamilton, Ontario. It also was

produced on a quarterly basis by a group of volunteers between 1994 and 1997. Each project provided a range of health information and viewpoints about the treatment and management of HIV infection.

The data for this chapter was drawn from several sources. First, between 1994 and 1997, I was involved in producing both publications. My analysis is informed by field notes written during all aspects of this participation. Second, in-depth semi-structured interviews were conducted with those involved directly in the two print media projects. This perspective provides an understanding of the projects that extends beyond my own personal experience. Third, the back issues from each publication were also a source of data. Previous issues are useful in illustrating the format, content and purpose of the publications. I started by looking at how *The Positive Side* and the *Treatment Information Flash* were produced. During this analysis, though, my focus broadened to include the ways in which print media have been used as a form of treatment activism within the AIDS movement in Southern Ontario. [1]

The chapter is divided into three sections. The first section provides a brief overview of AIDS treatment activism, and the PWA movement more broadly, in Canada. In the second section I outline the emergence, purpose, and eventual decline of *The Positive Side* and the *Treatment Information Flash* as specific, localized examples of the way print media have been used as a form of treatment activism. Lastly, in the third section I argue that working toward being and remaining 'community-based' is what has made publications like *The Positive Side* and the *Treatment Information Flash* distinct as forums for the production and dissemination of AIDS treatment information.

AIDS Treatment Activism

The PWA self empowerment movement has been built on the idea that people with HIV/AIDS need to be actively involved in those decisions that directly affect their lives. Understandably, involvement in decisions regarding health care has been a particularly important issue. For instance, the movement's founding statement, the "Denver Principles", outlines a series of rights concerning health care and living with AIDS. They include the right to quality nonjudgemental medical and social services, to full medical explanations of treatments and risks, to choose and refuse treatment modalities, to participate in research safely and without jeopardizing access to treatment, to confidential medical records, and lastly, to live and die in dignity. Since 1983, many of those involved in PWA organizing have engaged in various forms of activism in an attempt to have these rights realised, respected, and upheld.

Several books and articles have been written on treatment activism as an aspect of the community-based response to HIV/AIDS.[2] Much of this work has focused on the social significance of ACT UP. Crimp and Rolston (1990), for instance, have documented the group's political actions, highlighting their innovative and subversive use of cultural symbols about AIDS and sexuality. In a more analytic frame, Gamson (1989) has examined ACT UP as a new social movement, identifying the differences and similarities between radical direct action political groups and earlier forms of political protest. For Gamson, the particularities of ACT UP are a response to a more muted form of oppression, an "invisible and disembodied process of normalization," in which the state is less directly involved and identifiable as a target for political action. Epstien (1991), also, uses the actions of ACT UP as a lens through

which to examine how activists have, through their demonstrations and demands, transformed the way in which scientific research is conducted. In a Canadian context, Smith (1990) has written about AIDS ACTION NOW! (the Canadian equivalent to ACT UP). Smith looks at the social conditions which gave rise to AIDS ACTION NOW! as a community-based effort to address the support and health care needs of people living with HIV/AIDS. Overall, Epstein's phrase "science versus activism" captures the general intent of this work on ACT UP and AIDS ACTION NOW!: it illustrates how direct action groups have, through their collective efforts, forced social institutions like the medical establishment or government to be more accountable to those communities directly affected by HIV/AIDS.

The formation of direct action political groups - like ACT UP in 1987 - have been mistakenly thought to represent the origin of AIDS activism and the AIDS movement. For instance, in 1989, the journal *Radical America* featured a special issue on the AIDS movement. In the introduction, ACT UP was cited as the catalyst for the AIDS movement in North America even though AIDS organizing in the United States started as early as 1981 when the epidemic emerged. [3] Patton (1990) has been critical of such misconceptions, noting how quick and easy it is for the early community-based response to HIV/AIDS to be written out of discourses about the epidemic and subsequently forgotten. [4] ACT UP is only one aspect of the AIDS movement. It is also only one aspect of treatment activism by people living with HIV/AIDS. [5] In fact, organizing by and for people with HIV/AIDS has included efforts to develop education, support, and research initiatives that address the treatment and health care needs of those HIV infected and affected.

Recently, several books and articles have drawn attention to forms of treatment activism beyond direct action groups. Brown (1996), for instance, begins his analysis by looking at the role that ACT UP has played in AIDS organizing in Vancouver. Ironically, he finds that AIDS activism has largely occurred within the context of local PWA organizations. The BCPWA Society, he notes, has not only provided treatment advocacy for people with HIV/AIDS, but has developed a wide range of other initiatives related to health care, including research projects, providing access to alternative therapies, workshops and other educational forums. In a similar vein, Ariss (1996) has written about PWA organizing and treatment activism in Australia. He examines the ways in which a PWA organization in Sydney, called People Living with AIDS, addressed treatment issues by putting political pressure on the medical establishment through the media, started clinical trials on experimental AIDS treatments, and helped to make the ethical guidelines around clinical trials more responsive to the needs of people with HIV/AIDS. Similarly, Khan (1993) has written about community-based PWA organizations in the United States and Canada that have identified treatment or health care issues as central to their mandates. This research focuses primarily on the ways in which PWA groups have conducted their own research on alternative or experimental treatments. The formation of the PWA Health Group in New York is a good example. Khan notes that this collective not only pioneered community-based research on experimental therapies but also served as a buyer's club, providing a broad network of people with HIV/AIDS reasonably affordable access to illegal or controversial therapies, and as an information resource, publishing *Notes From The Underground*, a newsletter on alternative and complementary therapies. Most of the groups that are identified in the book are American; however, Kahn

does mention the BCPWA Society in Vancouver as an organization that has placed a priority on treatments and community-based research in its programs and services.

This literature provides a more diverse portrait of treatment activism; it suggests that education, support, and research for people living with HIV/AIDS were political initiatives akin to the demonstrations and protests of ACT UP and AIDS ACTION NOW! In a social climate largely hostile to the needs and concerns of people with HIV/AIDS, PWA organizations formed in order to provide treatment workshops, access to complementary therapies (as well as food banks, financial assistance, housing, and other health necessities) and evidence supporting the benefits and legitimacy of health care alternatives not endorsed by the state or the medical establishment. Such efforts by and for people living with HIV/AIDS were, in many cases, the only sources of education, support, and research that were available. Those communities most affected by HIV/AIDS needed to take action and helped each other because social institutions like the state failed to respond to their needs or interests. It is the community-based and oppositional nature of such projects that "qualifies" them as forms of AIDS activism. [6]

Community-Based AIDS Treatment Information Projects

A significant part of this type of treatment activism has been the production and dissemination of information about treatments and health management. Over the course of the epidemic, treatment information initiatives have been incorporated into the community-based response to HIV/AIDS in order to help those infected be aware of their health care options. Indeed, the importance of "staying informed" has always been high on the list of key

survival strategies for people with HIV/AIDS. [7] For the purposes of this project it is useful to situate the emergence of treatment information forums as part of more general efforts within the community-based response to HIV/AIDS to construct an alternative public sphere for those infected. Over the past fifteen years, the treatment forum aspect of this public sphere has been shaped by several factors including the changing needs of people with HIV/AIDS, developments of new treatments, wider access to new media technologies, and the ongoing development of community-based response to HIV/AIDS.

Early in the epidemic, in the 1980s, the problem that people with HIV/AIDS faced was a lack of information about new and potentially beneficial treatments. In response, people with HIV/AIDS formed social networks, often in close proximity to AIDS organizations, in order to share strategies to promote their health and manage their infection. Eventually, such forums were expanded and became, or were integrated into, print media projects. For instance, PWA newsletters, like the *BCPWA News*, began to offer more news and advice about the benefits, problems, and availability of new treatments. Also at this time, in the United States, people infected and affected by HIV/AIDS began to develop their own grassroots treatment publications. The most notable and enduring example is the *AIDS Treatment News*. Khan (1993:65) describes the circumstances surrounding the development of this publication:

> In 1986 John S. James began writing a column for the San Francisco gay publication the Sentinel ... . Eventually he established the *AIDS Treatment News*, an authoritative biweekly report on AIDS therapies in which he investigated new therapies and provided his readers with the history, the operating theory, the results of experiments and directions for making or obtaining substances.

As Kahn notes, the publication quickly became *the* source for information about conventional and nonconventional AIDS treatments. [8] Notoriety and popularity came in part because of John James' commitment, but also because there were few other forums for information available at this time. In James' words, as quoted by Khan (1993:64), "I shouldn't be doing this work. It should have been started by the government years ago, but either I do it or it doesn't get done." In general, with few information resources available through the state or medicine in this initial phase of the formation of an alternative public sphere about treatments, the onus was placed on groups of people with HIV/AIDS to develop their own means of sharing knowledge about health care issues.

With developments in the treatment of HIV/AIDS, the key issue for people with HIV/AIDS became gaining access to information rather than a lack of information. AIDS activists were angered that the knowledge and information produced about the treatment of HIV/AIDS was restricted to and controlled by health professionals and members of the scientific community. This monopoly was broken, at least symbolically, at the 1989 International AIDS Conference in Montreal when activists from ACT UP and AIDS ACTION NOW! took over the opening ceremonies and demanded access to and involvement in the conference proceedings. In the declaration of rights read at the opening ceremonies, titled the Montreal Manifesto, activists called for the establishment of an international treatment information exchange which would be accessible to all people infected or affected by HIV/AIDS. Pressure from the organized HIV/AIDS community eventually led to the development of and greater support for (from government and private foundations) treatment information organizations. In the United States, groups like Project Inform (PI) were

established which focused exclusively on interpreting medical information and making it available to people with HIV/AIDS. In Canada, a similar organization was started, the Community AIDS Treatment Information Exchange (CATIE), initially a subcommittee of AIDS ACTION NOW! and then as an autonomous organization.

With the rise of new medications and the use of combination therapy or treatment cocktails, as well as the rise in use and legitimacy of complementary therapies, the health care information needs of people with HIV/AIDS have grown exponentially. With these changes, treatment information organizations like Project Inform and CATIE have faced two main challenges in the 1990s. First, it has been necessary to make complicated scientific and medical information understandable and accessible. As a result, instead of print media organizations began to use the phone and the fax as an alternative means of disseminating treatment information. Second, more recently, the problem that many people with HIV/AIDS face is not the availability of information as it was in the 1980s and early 1990s (although accessibility continues to be a serious problem), but the overabundance of information. For treatment information organizations, simply making information available and understandable was not enough to help people with HIV/AIDS stay informed. Increasingly, organizations have had to develop ways of helping people with HIV/AIDS manage the available information so that they can make informed decisions about their health care.

Looking back at the treatment information initiatives over the course of the epidemic it appears that there have been two trends that have remained constant. First, the forums through which people with HIV/AIDS have exchanged information have continued to evolve from informal groups to the use of new media technologies. Second, despite the increasing

use of media technologies, the involvement of people with HIV/AIDS has continued to be considered essential to the production and dissemination of 'community-based' information about health care and HIV/AIDS. Each of these trends have had a significant impact on the construction of an alternative public sphere about health and health care.

The two publications included in this research, *The Positive Side* and the *Treatment Information Flash*, occurred during the middle period in the evolution of treatment forums for people with HIV/AIDS. Each was created in the 1990s as the PWA movement gained momentum. More and more people with HIV were interested in promoting their health and becoming involved politically often because their needs and concerns were, and had been, largely ignored. In his study of AIDS organizing in Ontario, Cain (1993a) has referred to this mobilization as the emergence of a politics of HIV. Increasingly, those infected with HIV/AIDS were demanding that they be actively involved in the programs and services created to address their needs and concerns. In terms of health and health care, as in the case of *The Positive Side* and the *Treatment Information Flash*, groups of people with HIV/AIDS organized and began producing their own local publications as a forum for information about treatments and the management of HIV infection generally.

Examining these two media projects in more depth is one way of better understanding the development of treatment forums by and for people with HIV/AIDS. The origins and decline of *The Positive Side* and the *Treatment Information Flash*, for instance, provided a glimpse of the circumstances surrounding transformations in the way treatment information has been produced and disseminated. Similarly, looking at the objectives of each publication illustrates the struggles among groups of people with HIV/AIDS to achieve and sustain a treatment

forum that remains 'community-based' in its perspective on health and health care. In conducting this analysis I begin by examining the historical development of each publication. Afterward, I look briefly at the role of these treatment information projects in the overall development of an alternative public sphere for people with HIV/AIDS.

The Positive Side

By the time that I started volunteering at CATIE, in 1995, *The Positive Side* had already been in existence for five years. My role initially was to coordinate communication between members of the collective that produced the publication: helping to arrange meetings, compiling a list of phone numbers, fax numbers, and electronic mail addresses, setting up locations and times to meet, and calling people about the articles that they were working on. After a few meetings, though, I began to edit, conduct research, and write material for upcoming issues. Over the next 18 months I contributed articles to *The Positive Side*, interviewed the members of the collective, shared e-mails, and talked informally over coffee about the project and about the AIDS movement in Canada. It was not long before I felt as if I was a part of the publication.

The origins of *The Positive Side* are linked to the rise of treatment activism in Canada in the late 1980s. This mobilization was a response, in part, to the fact that support and care for those HIV infected was still organized around the idea that HIV/AIDS was a fatal rather than chronic disease, despite the evidence to the contrary offered by people living with HIV/AIDS in Canada and the United States (Smith, 1990). This approach meant that the state and the health care professions were not concerned with advancing or developing initiatives which

would enhance or lengthen the lives of those HIV infected, like gaining access to new experimental treatments. Instead, programs and services were oriented more toward palliative and respite care for those in the very late stages of HIV infection. This limited public response to the needs and concerns of those HIV infected meant that it was necessary for AIDS activists to establish their own infrastructure to provide programs and services that emphasized living not dying with HIV/AIDS.

In Toronto, at this point in the AIDS movement, it was difficult for those involved in existing AIDS organizations to overtly challenge state policies for fear that this action might threaten the public funding that they received from government sources. Instead, activists formed AIDS ACTION NOW! (AAN!), a direct action political advocacy group that was separate from local AIDS service organizations. AAN! staged demonstrations, developed programs and services, and lobbied those in positions of power regarding AIDS care and support.

In terms of programs and services, AIDS ACTION NOW! considered the production and dissemination of treatment information as a part of its mandate. For instance, in the Montreal Manifesto activists called for the establishment of an international treatment data base that would be accessible to medical professionals as well as those infected and affected by HIV/AIDS. [9] In addition to putting pressure on government, those involved in AAN! also looked into ways of creating their own treatment forums. Starting on a local basis, a sub-committee of AAN! was established to gather and distribute AIDS treatment information. The main vehicle for this material was a publication called *Treatment Update*. Lobbying by AIDS activists eventually led to the federal government agreeing, at least in principle, that more

resources should be devoted to programs and services, like access to treatments and treatment information, that reflected a health promotion model of AIDS care and support. Soon after this commitment, the AAN! sub-committee acquired public funding and became a separate AIDS agency and became the Community AIDS Treatment Information Exchange (CATIE). [10]

The Positive Side emerged at the same time as CATIE became an autonomous organization. In 1990, those involved in CATIE felt it was necessary to establish an editorial board with the purpose of producing and overseeing publications about HIV/AIDS other than *Treatment Update*. A group of people infected and affected by HIV/AIDS responded to this request; most of whom had been involved in AAN! and AIDS organizing in Toronto. The collective felt that CATIE, as a treatment information exchange, needed to provide a broader range of health information to a more diverse cross section of people infected and affected by HIV/AIDS. *Treatment Update*, they argued, dealt almost exclusively with allopathic medicine and medical research and was oriented primarily toward members of AAN!, those involved in AIDS work, and professionals providing care to people living with HIV/AIDS. As one member of the collective explained,

> CATIE was just starting out - there might have been one staff member - and *Treatment Update* was great as a digest of all the new developments in medical treatments. It didn't really speak directly to people with HIV/AIDS, though. We thought that there was so much potential to get information about health care into the community - not just medical treatments but all the alternatives that people were starting to try.

Calling themselves the CATIE Publications Collective, the group's first decision was to recommend the development of a new publication called *The Positive Side*. As stated in the proposal submitted to the sub-committee (CATIE),

> the newsletter will be aimed at all HIV affected individuals, and in particular, those who do not have access to information available about this disease and its treatments. It will be written in a clear and understandable manner and may occasionally include articles from other publications.

The collective's agenda was twofold. They sought to create a forum that would provide a broad range of health information. And second, they wanted this forum to reach as many people with HIV/AIDS as possible. The overall objective of this media project, according to the collective, was to "encourage people with HIV/AIDS to be actively involved in making decisions and developing strategies to optimize their health care."

As a forum for treatment information *The Positive Side* was innovative in two ways. First, it highlighted the health care alternatives that were available, or becoming available, for people with HIV/AIDS. At the time of this project, treatment information meant, for the most part, information about allopathic medicine. Even within CATIE, Western medical treatments were endorsed, though not officially, as the predominant and preferred approach to managing HIV/AIDS. In proposing the publication to CATIE the collective wrote that they would,

> provide to HIV-affected individuals information which will enable a clear understanding of the full spectrum of treatments available, and a source of information on other HIV-related issues and organizations. Equal consideration will be given to all types of treatment modalities, whether allopathic, or what are referred to as complementary or nontraditional therapies.

During the early 1990s, there were few sources of information available about complementary therapies. *AIDS Treatment News* in the United States provided some information on

experimental treatments but did not have the scope to address complementary therapies in depth. The PWA Health Group produced a newsletter called *Notes from the Underground* but it provided information about buyers clubs, community-based research, and experimental treatments rather than complementary therapies. In Canada the situation was worse. Apart from the occasional article in newsletters like the *BCPWA News*, people with HIV/AIDS had almost no access to information about use of complementary therapies, or about how to take a complementary approach to their health care.

In Toronto at this time there was an emerging consciousness among members of the organized HIV/AIDS community about the potential of complementary therapies in managing HIV infection. One respondent told me that,

> I always knew some people who were into holistic kinds of medicine. It seemed like more and more people were getting into it - trying out alternative therapies - acupuncture, massage, looking after their diet - and doing really well. Soon there were workshops, programs like Body Positive and Rise that gave orientations. It seemed to be really taking off, but most people still didn't really know much about it and wanted to know more about it.

This turn toward alternatives was linked to broader efforts to develop forms of health promotion and self care among people with HIV/AIDS. It was also linked with the desire among many people with HIV/AIDS to not be dependent on Western medical institutions. The collective's core members were a part of, or least well connected to, this critical mass of people with HIV/AIDS interested in exploring and promoting alternative forms of health care. Consequently, *The Positive Side* focused primarily on complementary therapies and their use by people with HIV/AIDS, even though they originally planned to pay equal attention to all treatment modalities. As one respondent said,

My sense of *The Positive Side* was it was exciting and innovative. There was a real paucity of information about complementary therapies and we were a group interested in making this kind of information available. There simply wasn't anything like it. We often would make the argument that this project was important; that there really wasn't anything else available about complementary therapies in the Toronto area or in Canada for that matter.

Consistent with this view, in speaking with other collective members, they agreed that a forum like *The Positive Side* was needed to break the silence about complementary therapies and also to counterbalance the over emphasis that had been placed on allopathic medicine. It was going to be the voice of this expanding involvement and interest in health care alternatives among a growing number of people with HIV/AIDS in Toronto.

Information about complementary therapies was conveyed in several different ways. First, people with HIV/AIDS were asked to write stories about how they were approaching their health care. Contributors to this "Positive Living" section were selected by members of the collective in order to profile people with HIV/AIDS who were "taking responsibility for their health, and making treatment and life-style decisions which work for them." Initially such testimonials were written by members of the collective - telling their own stories about using health care alternatives. Eventually, personal accounts from a broader circle of people with HIV/AIDS were published in this section of the publication. Second, in each issue there was at least one article on the relevancy of nutrition to managing HIV infection. One member of the collective strongly believed that nutrition was an essential area of health care that was overlooked or misunderstood in allopathic approaches to promoting health and managing HIV-related health problems. Third, members would research and write articles about the therapies that they were using or considering. This material examined the advantages and

disadvantages of a therapy - naturopathy, massage, medication, herbal remedies, Chinese medicine, exercise, and so on - based on the available literature and on the author's personal experiences. Fourth, occasionally, articles would be written on particular health issue or problem related to HIV or AIDS. For instance, I collaborated with another member of the collective on an article on depression as a mental health issue for people with HIV/AIDS. In this type of article we outlined the different approaches to treating depression (highlighting health care alternatives and providing a critical perspective on allopathic medications), different strategies that people with HIV/AIDS have used to manage and address depression, and the community resources (AIDS service organizations primarily) available if a reader was concerned about mental health problems arising from HIV infection.

The Positive Side was also considered to be innovative in the way that it produced and disseminated health information. It was important that the collective consist primarily of people with HIV/AIDS. This membership was thought to ensure that the material in the publications was from the perspective of those living with HIV/AIDS. According to one respondent, a person who came to the group after it was formed, *The Positive Side* was distinctive because

> It was 100% volunteer driven; we did all the work. It was exciting for me to see a project that was part of an AIDS organization function autonomously. It was also an innovative way of conveying information because the majority of people involved were HIV positive. That was really cool; it was seen to be very empowering for those involved and for the HIV/AIDS community.

Creating a forum for HIV-related health information that was produced by and for people with HIV/AIDS was the collective's central objective. They also, however, placed a high priority on having this forum reach, and potentially include, a broad spectrum of people

infected and affected by HIV/AIDS. According to the collective, *The Positive Side* would be made available to

> **all** AIDS/HIV-affected individuals regardless of sexual orientation, sex, age, or racial origin. And, that efforts will be made to distribute this publication to personnel from health and social service agencies, and to relevant organizations across Canada (e.g. HIV clinics, and gay and lesbian organizations). In addition, the publication will be circulated to a selection of AIDS and media organizations in the United States.

CATIE paid to have copies of *The Positive Side* sent to members of the organization along with its other publications. This conventional approach to distributing PWA media ensured that *The Positive Side* would reach health and social service agencies and selected AIDS organizations in Canada and the United States.

What the collective had envisioned, though, was a forum that would be directly available to people with HIV/AIDS, especially those with limited access to treatment or community resources. In other words, they wanted the information to reach those people who needed it the most and would have the hardest time gaining access to information through formal or informal channels. As one person said

> I want *The Positive Side* to reach people who don't yet have a clue about managing their health. I want to reach the young guys on Church Street hanging out of the windows; the ones who don't know what options are available to them or even think that HIV infection really affects their health.

One of the key barriers to conveying health information, it was thought, was that people perceived advice about their health as being too boring, frightening, too moralistic in tone, and quite often so laden with scientific jargon that it was impenetrable.

In order to try to address some of these issues the group started to convey information in a way that was interesting and understandable. Otherwise they felt that many people with

HIV/AIDS would not put the effort into reading the publication. During our regular meetings we would have long conversations and debates about how to make information about health care interesting. For instance, a series of articles on digestion was titled "You and Your Gut" in an attempt to make it more compelling and understandable. Also, the collective chose to use a tabloid format so that the publication would appear less like an 'official' document or a newsletter produced by a government agency. There were also debates as to how to incorporate graphics, photos, and elements of popular culture into the format of *The Positive Side*. In the words of a group member primarily involved in the desk top publishing side of the publication,

> Every issue I tried to improve upon the look and feel of the publication a little bit - adding photographs of the contributors, trying to use graphics, changing fonts, making sure that the page didn't seem cluttered. But I was doing a lot of this stuff at my work; and it was becoming hard to find the time. We didn't really have the technology to create the kind of publications that we all or at least I envisioned. It never looked really poor but it wasn't really slick either. I felt that took something away from its potential a bit.

Unfortunately, in terms of style, as this person suggests, the group did not have the resources to make many of the changes that were proposed. As a volunteer project there was not a budget for the publication other than the costs of printing and distributing each issue. Anything above that in terms of making the publication more appealing - like more professional desktop publishing software - had to be supplied by members of the collective.

Style and clarity was an ongoing issue, but did not address the inadequacies in the way that most treatment information was distributed. As an alternative, the collective approached *Xtra!*, a Toronto gay publication, and asked if they would distribute the publication as an insert. This was proposed to CATIE as follows:

The Collective has reached an agreement with *Xtra!* magazine (circulation 22,000) to produce and distribute copies of the newsletter with regular issues of *Xtra!* and to absorb the associated costs (about $300 per issue). The distribution will coincide with the publication of *XS*, *Xtra!*'s monthly <u>national</u> news supplement which appears in the first issue of each month. This approach will reduce production and distribution costs.

The idea was presented as a cost saving measure, but it was intended more as a tactic for getting the publication out to gay communities and in the hands of people with HIV/AIDS. It was understood by the collective as a symbiotic relationship between the two print media. *The Positive Side* benefitted because of the wide and targeted distribution; by doing this service for free *XTRA!* also benefitted because they were seen by readers as having a commitment to the fight against HIV/AIDS and to the needs and concerns of people with HIV/AIDS.

A less pressing issue that the collective tried to address regarding accessibility was reaching a diverse cross section of people with HIV/AIDS. In Canada, gay men represent the largest group of people infected with HIV. For many years, though, it has been widely acknowledged that an increasingly diverse group of people are now infected with HIV: women, people of colour, injection drug users, youth, haemophiliacs, and so on. Moreover, there is a wider acknowledgement that the identities of those infected are not singular or discrete. For instance, there is greater recognition that gay communities are not homogeneous; they consist of men and women from different social and ethnocultural backgrounds who may also identify as injection drug users or as haemophiliacs. As the spread of disease continues, it appears as if HIV infection is becoming most prevalent among many communities that are systematically marginalized or disadvantaged.

The Positive Side collective consisted primarily of HIV positive gay men. They were, as a result, aware of the need to provide information to a diverse range of gay men with HIV/AIDS. It would be accurate to say that gay men were considered to be the primary readership, as indicated by their choice of *Xtra!* as a form of distribution. As one member noted, despite this awareness of diversity, much of the material in the publication still reflected their own status as primarily white, middle class gay men:

> The collective was founded by middle class gay white men of a particular generation. That was an issue too. I don't think it was matter of being against providing different information; it had more to do with not knowing who or where to go to get this information. A more diverse range of people were suggested for contributions, in order to get a different perspective, but, often at meetings when names were suggested it would be this long list of gay white men and then one or two other people. I think in the end when you look at the publication the majority of those who were published in it were gay white men.

Later in the publication's history, more efforts were made to provide the views of other people with HIV/AIDS, particularly women, who needed health information that was tailored to their own particular health problems and social circumstances. The collective was aware of the need to provide more information that would be relevant to the needs and concerns of youth, women, and people of colour. For instance, in selecting people with HIV/AIDS for the viewpoints section of the publication, the group began to try harder to encourage women and people of colour to write about the way they approach their health care. The highlight of these efforts was a vibrant account by an aboriginal woman with HIV/AIDS. She began by writing, "BooHoo! I am a 42 year old Two Spirited Grandmother of the First Nations. I am Cherokee. I belong to the Wolf Clan and my Anishnawbe name is Wabun Au Kwe."

The problem of diversity was made easier for the collective when a woman of colour joined the group several years after the publication began. When we spoke about her involvement, she said that

> when I got involved one of roles I wanted to play was looking at women's health issues because it just isn't addressed, here or anywhere, really. Last year I had the opportunity to attend a conference in the United States and I looked specifically for advances in health care for women with HIV/AIDS so I could write about it in *The Positive Side*. It was hard going but I came back with a couple of items that I thought would be beneficial to women.

From our conversations, my feeling was that, as a woman of colour, she felt supported by the group, but still considered the task of representing women's issues a real challenge because she was not part of the initial collective and came to the group with a distinct and different perspective.

Until 1996, the collective had been successful in creating a forum about health care and HIV infection that was distributed to a broad range of people with HIV/AIDS. Unfortunately, at this time, several intersecting circumstances threatened the continuation of the publication. First, the person who had played a leadership role in *The Positive Side*, Sean Watterson, died of AIDS. The project continued after his death, but no one from the group was able or willing to take a leadership role with the publication. This accentuated the already loosely structured process involved in producing each issue. Delays ensued and it was not long before the collective began having problems getting issues ready for distribution, even on a quarterly basis.

Second, the organizational ties that the collective had established and relied on began to falter. *Xtra!* was no longer willing to distribute the publication as an insert for free or at a reduced cost. This perceived lack of support infuriated some members of the collective:

> Our reaction was that they were being arrogant. They hadn't addressed HIV/AIDS for so long and we had been providing them a means of avoiding criticism from the gay community and now they were pulling out. We said it was important for them; that they were not doing enough for HIV or AIDS. Soon after they came up with their own column on HIV and AIDS related concerns and said that we could forward our articles to them.

Xtra! did not accept the arguments made by the collective claiming that they simply were not able to afford to provide this service. They were still willing to include *The Positive Side* as an insert but the costs would have to be paid by CATIE and there had to be specific limits on size and adherence to a more strict schedule in terms of having each issue ready for distribution.

In addition to the problems with *Xtra!*, organizational changes at CATIE also had an impact on the publication. The organization had inherited the federal government's long awaited plan for a national treatment data base. CATIE received increased funding in order to become a national AIDS treatment information network. In a very short period of time the organization had to transform itself from being a sub-committee of AAN! to one of the largest AIDS service organizations in Canada. This organizational flux had serious implication for *The Positive Side*. As one staff member at CATIE noted,

> Because the publication had the CATIE name on it the executive director asked that we keep a closer tab on the editorial material. There was some board discussion about that - not because there was a horrible article published or anything - but because we were becoming a more serious organization, we had been around for a while, we were beginning to expand, it was time to pay more attention to these kinds of things. It was not about concerns about the group or the information, it was

around the organization getting larger - we needed to rein in all the programs and review them on a more regular basis because before that it had become really informal.

A concern over editorial content eventually expanded into a broader debate not only about the status of *The Positive Side* as an entirely volunteer controlled project but also on the appropriate ways in which the organization should provide information about complementary therapies. [11] It soon became evident that *The Positive Side* would have to be incorporated into CATIE's revised organizational structure. At this point the collective had, for the most part, become disconnected and disillusioned; they baulked when CATIE asked them to become involved as volunteers in developing a standardized process in which to collect and distribute information about complementary therapies. The combination of factors proved to be too much for the collective:

> After the problems with XTRA!, the loss of Sean, and the internal debate regarding the value of *The Positive Side* as a reliable, credible, and effective means of providing information about complementary therapies, there simply wasn't the energy among those remaining to keep the project going - in fact, I am surprised it lasted as long as it did.

After the meeting with the executive director several of the members were interested in continuing *The Positive Side*. We talked briefly about approaching other AIDS organization for their support. However, after a short discussion the group quietly, almost silently, decided to disband. [12]

Treatment Information Flash

Between 1995 and 1997 the *Treatment Information Flash* was produced by the Hamilton AIDS Network. In years prior to this research I had contact with the AIDS Network through

other research projects. By word of mouth I learned that the organization was planned to start a treatment information project. This research had just started so I asked to become involved assuming that they would be starting a treatment publication. Soon after the project began, a small group of us, mostly volunteers, began the *Treatment Information Flash*. The publication was produced and distributed on a quarterly basis.

The treatment activism that gave rise to *The Positive Side* in the early 1990s also provided the foundation for subsequent treatment media projects. Organizing around health care issues raised awareness about the need for information about advancements in the treatment of HIV infection. And more directly, early treatment publications like the *AIDS Treatment News* provided the blueprint for later efforts to produce and disseminate information about managing HIV/AIDS. The *Treatment Information Flash* was also modelled directly after the treatment publications that had been produced by CATIE since the early 1990s - specifically, *Treatment Update* and *The Positive Side*.

In addition to a lineage of publishing treatment information among people infected and affected by HIV/AIDS, there were other factors that contributed to the emergence of print media projects like the *Treatment Information Flash*. First, organizing by people with HIV/AIDS had become more broadly based, growing in scope and size, but more significantly, it was no longer limited to large urban centres. In previous years, regional settings like Hamilton have lacked the necessary critical mass of committed individuals with similar interests needed to sustain a grassroots PWA movement for any extended period. In many cases, people in rural areas feel the need to move to larger urban centres after learning that they are HIV positive; mobilizing efforts, as a result, have suffered from this migration

to large urban centres (Cain, 1993a). [13] Currently, however, people with HIV/AIDS in less populated areas are having more success in organizing, with greater numbers and more support, which in turn, has helped to create projects - like treatment information publications - that directly address the needs and concerns of people living with HIV/AIDS

Another factor that has been influential in the development of projects like the *Treatment Information Flash* is that by 1995, the tenets underlying the PWA movement - particularly the need for people with HIV/AIDS to be actively involved in the decisions that affect their lives - had been, at least in principle, widely acknowledged as a priority within the community-based AIDS movement. This shift in perspective has been referred to by Roy (1995) as the emergence of a new AIDS agenda within AIDS organizing. The impact of this change has been twofold. First, AIDS organizations have become more committed to facilitating and fostering the active involvement of those HIV infected. And second, organizations have become more open to the idea of developing new programs and services, and revising existing programs and services, in order to better meet the needs and concerns of people living with HIV/AIDS. Over time, there has been more commitment to developing projects like lifestyle workshops, subsidised medical treatments, providing access to complementary therapies, sponsoring affordable housing initiatives, and starting and supporting media projects and public forums like the *Treatment Information Flash*. It was also assumed that people with HIV/AIDS would play a central role in the operation and provision of these programs and services.

Both the expanding PWA movement and the rise of a new AIDS agenda contributed directly to the development of the *Treatment Information Flash* at the Hamilton AIDS

Network. In terms of the PWA movement, on several occasions since the early 1990s, people with HIV/AIDS had tried to mobilize collectively in Hamilton, with varying degrees of success and with varying degrees of support from the Hamilton AIDS Network. [14] One of the projects that people with HIV/AIDS started in association with the Hamilton AIDS Network was a PWA publication. The *PHA Messenger* was started in 1994 by a small group of volunteers with HIV/AIDS who sought to continue a publication that had existed years earlier, started by a former group of politically active people with HIV/AIDS [15]. Soon after it began, the *PHA Messenger* was halted because it had drifted too far from the organization's core programs and services. [16] When the *PHA Messenger* was discontinued there were still volunteers, many HIV positive, still interested in working on a media project.

> I was frustrated with the *Messenger* because - well - let's just say some people were harder to deal with than others. It seemed all over the place which was too bad because I thought it was a good idea. After a while I just couldn't do it anymore. With certain people I could see starting again. I like to do that kind of stuff.

It was thought that the *Treatment Information Flash* would be a more practical and purposive alternative to the *PHA Messenger*. This project was in part driven by the efforts of local people with HIV/AIDS to remain actively involved in AIDS organizing.

The decision to create a treatment media project was also shaped by efforts of AIDS organizations to be more responsive to the needs and concerns of people living with HIV/AIDS. For several years the Hamilton AIDS Network had tried to revise its support services so that they incorporated elements of health promotion for people with HIV/AIDS. They had been criticized, however, for not making people with HIV/AIDS more of a priority. In response, the organization began to make a more genuine effort at addressing the needs

and interests of those infected with HIV/AIDS. For instance, an education project regarding information about treatments was started because clients had expressed a need for more assistance in the area of health care. In fact, one of my initial activities as a volunteer was to help develop a survey that would give some indication of the treatment information needs of local people with HIV/AIDS. When the *PHA Messenger* was discontinued and people with HIV/AIDS no longer had a local forum, it made sense to add a treatment publication that would be produced by and for people living with HIV/AIDS. Rather than an education project, the publication became an initiative of the peer support program - the goal was for it to be controlled exclusively by people with HIV/AIDS. Subsequently, the *Treatment Information Flash* became the latest of several failed attempts by the organization to effectively address the needs and concerns of those HIV infected and affected.

Officially, the *Treatment Information Flash* began when a group of us met for the first time to sketch out our plans for the project. It was led by the peer support coordinator and attended by half a dozen volunteers, a minority of whom self identified as HIV positive. After some discussion we identified two primary objectives. The first was to create a forum for health information that would, whenever possible, reflect the perspectives of those infected or affected by HIV/AIDS in Hamilton and the surrounding area. The second was to use the publication as a means of fostering a closer relationship between the Network and the local HIV/AIDS community (which was identified as those living with HIV/AIDS and those who provide services or care to those HIV infected or affected). The size and style of the publication was sparse because of limited resources; it was produced using the organization's computer and photocopier and looked very much like an agency newsletter. Despite this, over

the next two years we meet regularly and worked together to publish an issue every three months in as engaging and informative manner as possible.

In producing the *Treatment Information Flash* our group sought to create a forum that would help guide readers in their efforts to make sense of the information about the health care options available to them and help them work toward developing an approach to managing their infection. In the mid 1990s there were many advancements in the treatment of HIV/AIDS. These developments were promising. However, for those wishing to make informed decisions about their health care, keeping up to date and staying informed required a tremendous amount of time and energy, even with the guidance of a primary care physician and specialists. New medications were being introduced on a regular basis, but often it was difficult to know which were available or how to gain access to them. Health professionals were advocating the use of combination therapy, meaning that people with HIV/AIDS had to use a variety of different medications concurrently. In many cases several different combinations were tried before the side effects were reduced to a manageable level. Also, a new way of measuring the progression of HIV infection in the body, viral load testing, was introduced and used in conjunction with prior methods. Learning about the advantages and disadvantages of new health care options available, or trying to learn more about the results of a particular blood test, often required working through material, much of which was published in medical journals or AIDS periodicals, that was complicated, confusing, and at times contradictory. Finally, in addition to allopathic medicine, the use of a complementary approach to managing HIV infection was also becoming increasingly popular. People with HIV/AIDS were exploring and using a myriad of different medicines and therapies in

conjunction with allopathic AIDS medications. Learning about these therapies, and keeping up to date, was also a potentially overwhelming task for those HIV infected or affected.

Creating a forum that would help guide people through their health care decisions was a difficult task. It meant, first of all, trying to make the material in the publication relevant to the needs and concerns of people living with HIV/AIDS. We tried to do this in several different ways. While planning each issue, we paid particular attention to the ideas and views of those in the group who were HIV positive. We also actively solicited - both directly and indirectly - the views and perspectives of people with HIV/AIDS in the Hamilton region.

> A key to the success of this project is the inclusion of the diverse perspectives of people with HIV/AIDS. So, go ahead! Speak your mind. Have your say. Shout and Scream., if you need to. The possibilities are endless ... Complain about the side effects of 3TC. Advise other people with HIV/AIDS about the tastiest nutritional supplements. Or wax poetic about your latest massage. We'll even arrange for somebody to write the article for you, if writing is on your list or things you like to avoid ... right up there with cockroaches and root canals.

Similar to *The Positive Side*, the first section of the publication was devoted to submissions from people with HIV/AIDS. In writing and researching articles, volunteers were encouraged to talk with local people living with HIV/AIDS about their experiences, opinions, and advice. As a peer support project, the coordinator also tried to keep in touch with concerns brought to him by clients accessing other services offered by the Network.

In terms of the type of material represented in the publication, we tried to strike a balance between allopathic and complementary medicines. Many of the articles tried to address health in a broad context, looking not only at medications but also at the problems of cost or access or the relationship between poverty and the health needs of people with HIV/AIDS. Particular

attention was devoted to ensuring that the content was written in a way that a lay person

could understand and that helped people make practical decisions about their health care.

Despite these efforts, as a group, we were never convinced that our work was in fact

effective in reaching local people with HIV/AIDS:

> This is the third issue of the new and improved *Treatment Information Flash*. We continue to receive favourable comments from readers, as well as helpful suggestions. Unfortunately, we have not yet heard from many people living with HIV/AIDS. This project is intended to be peer-based and primarily serve the treatment information needs of people living with HIV/AIDS. Call if you have suggestions about how to make this project more accessible to you. **Your Voice Should Be Heard!**

According to one member, in reference to those injection drug users with HIV/AIDS, one

main problems was the language used in the articles; it was too sterile and not compelling

enough to attract and keep readers, even after several attempts at editing.

> People I know, people out there on the streets, in the East end of town, they don't talk like this. Most of what we have done doesn't really say anything to them. It is not in their own language so why are they going to read it. I mean we do the best we can, but why would they pick something like this up and read it? What does it say to them? Not much, I think. I'd like it if we could get closer to the way people with HIV/AIDS actually live and think day to day.

In the end, our attempts to get feedback about the publication and our attempts to make

revisions was largely ignored, although not everyone held this opinion, for many people with

HIV/AIDS the *Treatment Information Flash* was considered to be yet another source of

information to read. The comments we did receive were mostly from the local health care

professionals who were helping us distribute the publications. They said that people with

HIV/AIDS were taking the publication but they did not have any sense of what they thought

of it nor whether it was informative or relevant in terms of making health care decisions.

The limited and passive response to the publication by people with HIV/AIDS was not a surprise to the group. In fact, it spoke to our second objective - to mend ties between the Network and the HIV/AIDS community. Many of the people that I spoke with remarked that historically the Network did not have a strong reputation as a resource for those infected and affected by HIV/AIDS. As a project that was intended, in part, to redress this image, attention was devoted to making links with those in the HIV/AIDS community. Our group consistently tried to encourage people with HIV/AIDS to become involved in the publication as members or as regular contributors.

In some respects we were successful. During the life of the publication, there were new members with HIV/AIDS that joined and several others who contributed articles and personal accounts and regularly made themselves available if needed. The ideal situation, however, was for the *Treatment Information Flash* to be 'taken over' by a group of volunteers, the majority of whom would be either infected or directly affected by HIV/AIDS. This never did occur. The peer support coordinator and another staff member, involved as a volunteer, provided most of the continuity and commitment that was required to sustain the ongoing production of the publication.

More concerted efforts were made to connect with those involved in providing local health care services for people with HIV/AIDS. We approached health care professionals who were directly involved in AIDS care and asked them for their involvement and assistance. At one point, a primary care physician and a nurse in charge of clinical trials from a hospital immunology clinic joined the group and participated by writing updates on what services were available locally for people with HIV/AIDS. With their assistance and connections, we

received some funding to start a journal reading group for those interested in meeting and discussing the latest news and information about AIDS treatments. We gave copies to all of the local primary care physicians with HIV positive patients. We also ensured that extra copies were distributed to local health clinics, libraries and hospitals as a way of increasing the distribution of the publication beyond the clients and membership of the Network.

In this regard, using the publication as a form of outreach was successful. At least for a short period of time, we helped to facilitate a network of health care providers and people with HIV/AIDS who worked together on the same treatment information project. The publication also helped to facilitate improved relationships between AIDS workers at the Network and local health care professionals who provide HIV/AIDS care. In previous years there had been limited communication between the Network and the medical community.

The decision to discontinue the *Treatment Information Flash* was made for several reasons, but mostly because there were too few available resources. On a pure economic basis, it was costly to produce a 10-15 page publication and have hundreds of copies distributed to clients, membership and the local community. It became too difficult to justify using the agency's administrative resources for this purpose. Instead, a decision was made to produce a smaller and more general agency newsletter which provided some basic information about the treatment resources available at the Network and in the Hamilton area. Apart from costs, it was clear that there were not enough volunteers - HIV positive or negative - willing to invest the time and energy required to sustain the publication. Often volunteers for the Network were more interested in positions more directly connected to people with HIV/AIDS rather than something indirect like a publication. Occasionally new volunteers would begin

with the *Treatment Information Flash* but then would soon move on to other activities that they found more meaningful and intensive or less time consuming.

There were other factors at work beyond the lack of available resources. When the publication was being produced, the peer support coordinator had applied for funding to develop programs for people with HIV/AIDS that were based on a peer model of service delivery. When the funding was received there was an opportunity, facilitated by the Community AIDS Treatment Information Exchange, to develop a treatment centre consisting of a small room with books, journals, periodicals and a computer with Internet access. The *Treatment Information Flash* was always considered to be part of a broader plan to address the health care needs of people with HIV/AIDS, though for several years the publication was all that was offered. The centre would be run by people with HIV/AIDS who were trained as treatment information counsellors. Many of the volunteers who were involved in the publication decided to also become treatment counsellors. For a short period of time there was talk of making the *Treatment Information Flash* a project of the centre. However, eventually the decision was made to end the publication and devote any remaining resources to promoting the treatment information centre. Although the publication may not have been a complete success, it did help to provide the groundwork for an alternative, perhaps even more effective, means of informing people with HIV/AIDS about their health care options.

Treatment Information Projects in Southern Ontario

In closing this section, it is evident that *The Positive Side* and the *Treatment Information Flash* were both products of an emergent treatment activism, driven by people with

HIV/AIDS, within the AIDS movement in southern Ontario and perhaps also across Canada. Both challenged orthodoxies regarding the support services available to people with HIV/AIDS, the nature of medical information, and the conventional understanding of AIDS patients as passive and dependent, rather than informed and pro-active. The timing and locale of each publication, even though they were only a few years apart from each other and relatively close geographically, made each project unique.

The Positive Side was a spontaneous grassroots publication. It emerged in order to counter the lack of treatment resources available to people with HIV/AIDS. A collective of people living with HIV/AIDS mobilized to start it because they knew, from their lived experience, that this disparity was a problem, even before it was widely acknowledged within the AIDS movement. As a result, *The Positive Side* is more clearly an example of PWA self help and self empowerment.

In contrast, the *Treatment Information Flash* was constructed intentionally as a means to assist people in their attempts to interpret and make sense of an abundance of often overwhelmingly complicated information about advancements in the treatment of HIV infection. However, it was intentionally created as a way of fostering or facilitating PWA self empowerment and community development because the needs and concerns of people with HIV/AIDS had for many years been ignored and had more recently become recognized as a more pressing priority within the AIDS movement.

Unfortunately, changes in the approach to the provision of information, fuelled by the increasing complexity of managing HIV infection and by increases in public support for AIDS support services, made locally produced and small scale print media projects like *The Positive*

Side and the *Treatment Information Flash* redundant and increasingly obsolete. Contributing to this decline was the general lack of response to each of these forums among people with HIV/AIDS. The active involvement envisioned by those involved never really came to fruition; perhaps because expectations regarding the way in which readers would participate in the project were set too high. There was not a flood of people with HIV/AIDS wishing to express themselves or share information about their approach to health and health care. When the legitimacy and relevancy was called into question, and the projects were threatened, there was no outcry from their readers. In each case, apart from a few people who wrote letters and made phone calls, the majority of people with HIV/AIDS remained silent at the prospect of losing a print based forum for treatment information.

It has been difficult for those involved, particularly those initial members of *The Positive Side* collective, to accept the changes that have contributed to the decline of their projects. On several occasions they have attributed the decline of their project to the increasing institutionalization of AIDS organizations.

> I felt that when CATIE began to expand - when they got the additional funding - things began to change. There wasn't the same atmosphere - it was much more formal and ... cautious. I didn't know anyone there anymore. It made me want to pull back, question my involvement in *The Positive Side*. Before it was always our publication and CATIE was helping us along; now it seemed like it was their publication and changes were going to be made along with everything else.

At the same time, though, most of the group have adapted to the organizational changes that have occurred at CATIE and at the Network. They have continued their work in another capacity, like working on other publications, helping to develop a means of evaluating complementary therapies, or by becoming treatment counsellors. As one person told me,

It is a trade off, I guess the information that is produced now seems more impersonal and not broad enough in scope. That was what we tried to do with *The Positive Side*. At the same time, though, CATIE is doing the best they can, a lot of good things, really - getting people involved, working with local groups, making information available. In the end that is what is important, I guess. It still makes me sad, though, when I think about it."

On the Significance of Treatment Publications

With the discontinuation of publications like *The Positive Side* and the *Treatment Information Flash*, it is instructive to step back and examine their significance as forums for information and opinions about managing HIV/AIDS. There are two factors that were pivotal to the role of treatment publications in helping to construct an alternative public sphere for people with HIV/AIDS: (1) the importance that is placed on becoming and remaining community-based media projects; and (2), the use of different types of media as a means of conveying treatment information. A discussion of these factors as they apply to *The Positive Side* and the *Treatment Information Flash* helps to illustrate why they are distinct from sources of information about the treatment and management of HIV infection.

Community-Based Media

As products of the PWA movement, *The Positive Side* and the *Treatment Information Flash* have been influenced by the idea of being and remaining 'community-based' media. What constitutes community-based media has been taken up, in several different ways, in the literature on media activism. For instance, Downing (1984) has examined the experiences of those involved in 'self managed' media projects. In this analysis he illustrates how control over production is crucial to media projects that focus on challenging or resisting forms of

political oppression. External influence or control only threatens to subvert collective efforts directed at achieving self representation. Smith (1993) looks at this issue in a different way, arguing that it is important to make the distinction between print media for women and feminist print media. According to Smith, the former tend to reflect the dominant gender order, contributing to the social forces that oppress and marginalize women, in part, because they do not focus on addressing or advancing the needs and concerns of women. Feminist media, in contrast, tends to be informed by a political analysis of gender: they are created and produced by and for women; they provide a forum for the voices of women who have been silenced through oppression or marginalization; and they challenge and seek to transform patriarchal social relations. Trend (1993) takes this point further in his critique of media projects that have been informed by Leftist politics. The problem, he argues, has been that the media created or influenced by Leftist politics have been dominated by an intellectual elite that have ignored or chastised the voices and opinions of those who are oppressed or marginalized by the dominant social order. [17] As an alternative, Trend looks to recent efforts among gay and lesbian media activists who have turned to new media technologies and their own experiences as the basis for subverting and challenging homophobia and hetrosexism.

For each of these scholars, community-based media follow what might be called a peer model of communication: a specific group using media to speak for themselves and in doing so achieving some degree of self representation. Added to this peer model is a political analysis of, and opposition to, the dominant social order. In this sense, media self representation is directed at supporting marginalized communities and transforming or challenging oppressive social and institutional forces. A key issue raised in this work is how

those involved in media projects understand and negotiate this community-based status through their efforts at achieving self representation. In the case of *The Positive Side* and the *Treatment Information Flash*, subscribing to this idea of being community based was essential to create a public forum about health care for people with HIV/AIDS.

What community-based meant for members revolved around ensuring that the projects were "by and for people with HIV/AIDS" or "grounded in the experiences of people with HIV/AIDS" or at least that they "take into consideration the perspectives of those infected and affected by HIV/AIDS." More specifically, this understanding of community-based had two components. First, it was an attempt to remain accountable to the needs and concerns of those HIV infected and affected. And, second, it was an effort to privilege and foster the opinions, views, and expertise of those living with HIV/AIDS. Achieving this required a political analysis that identified the dominant social order as working against, or simply ignoring, the best interests of those HIV infected and affected. In response, people with HIV/AIDS needed to take control of the production and representation of information about managing HIV infection. As a result, becoming and remaining 'community-based' was an ongoing process that was negotiated among those involved in the two media projects. It was seen as essential to providing an alternative forum for health care information that looked critically and pragmatically at dominant discourses about managing HIV infection.

This process of working toward becoming a community-based project occurred on three levels. First, on the level of organizational sponsorship, each media project was controlled by a group of volunteers - people living with HIV/AIDS - but supported, and, for the lack of a better term, governed by an AIDS service organization. This sponsorship created an

ambiguous relationship between the groups and their governing organization. In some

instances, being affiliated with an AIDS organization was considered to be a source of

strength as it meant that the media project was tied to the broader AIDS movement (the

community-based response to the epidemic). In articles about health issues and HIV infection,

AIDS organizations were almost always cited as valuable community resources for people

living with HIV/AIDS. The following excerpt from *The Positive Side* is typical:

> There are a number of options available for managing and treating depression. It may
> be helpful to turn to lovers, friends, other people with HIV/AIDS and family for
> emotional and social support. Depending on your situation, this may or may not be
> an option. It can be difficult to build or maintain a social network, but the benefits
> of feeling connected to a community often outweigh the costs. Local community-
> based AIDS organizations offer counselling and support groups for people with
> HIV/AIDS with a variety of different needs. These include programmes and
> workshops which are designed to help develop skills for managing HIV or AIDS.
> AIDS organizations provide other support services, as well, including financial
> assistance, a food bank and other types of practical support. They can be a potential
> source of information on the use of complementary therapies in the management of
> HIV disease. Many have developed health promotion programmes that can be
> beneficial in managing mental and physical health problems.

At the same time, though, those involved in *The Positive Side* and the *Treatment Information*

Flash were aware that AIDS service organizations were becoming increasingly tied to

government and to AIDS industries. Partnerships such as these were considered by many to

potentially work against the best interests of those HIV infected and affected. As one

respondent from the *Treatment Information Flash* noted: "Sometimes I don't know what is

up with this organization. They seem to be caught up with looking over their shoulder that

they don't have a sense of what they are here for - people with HIV/AIDS end up just getting

swept under the rug."

As a result of these tensions each project tried to achieve a status that was semi-autonomous from their sponsoring organization. In the case of *The Positive Side* this distance was made explicit; the collective viewed themselves as representatives of the HIV/AIDS community who were making use of the resources offered by CATIE as a community-based AIDS organization. When this arrangement was threatened, the collective disbanded. As one member of *The Positive Side* collective told me,

> from where I sit CATIE does seem to be committed to producing *The Positive Side*. It is something that is a perk; if it gets done it gets done and that is fine. But that is not their focus. It is not that they don't like *The Positive Side* or that it is a good idea it is that they have other things to worry about - it is an arm's length little publication - and that is what we were. We organized things so well that they didn't think they had to worry about *The Positive Side* because we were so self sufficient - we did such a good job it just does itself. And that is what we wanted - that is what we submitted in our proposal.

In regards to the *Treatment Information Flash* achieving some level of autonomy was considered to be an objective to work toward rather than something to defend. There simply were not enough volunteers willing to support the publication as an entity separate from a sponsoring organization, even though the group tried to connect with and involve local people infected and affected by HIV/AIDS.

Thus, for the two groups, being community-based meant, at least in ideal terms, establishing themselves as a bridge between the HIV/AIDS community and AIDS service organizations. This intermediate position allowed them (literally in the form of resources) to write, speak freely, and remain connected and responsive to the needs and concerns of local people with HIV/AIDS. Inevitably, though, this approach was problematic in that it marginalized the groups from their sponsoring organizations and from an HIV/AIDS

community that did not really care (or possibly even exist) enough about the publications to provide feedback or to become involved. [18]

At the level of production, the meaning of community-based was tied closer to the idea of a peer model of communication. This was expressed and defined in two ways. First, it was stressed that membership in each group be limited to an individual's relationship to the epidemic. In other words, contributors were either infected or directly affected by HIV/AIDS. Other volunteers who did not define themselves in this way were welcomed, but kept at a distance and made aware, mostly implicity but also explicitly, that HIV status served as a the foundation for the project. Other forms of expertise, if a person was a health professional, a former magazine editor, or a social scientist, for instance, were considered to be valuable but secondary and potentially problematic. When I asked to become involved in *The Positive Side*, one of the core members kindly and subtly informed me that the publication was about the perspectives of those living with HIV/AIDS and that my contributions would have to first and foremost take that into consideration. At the *Treatment Information Flash* fewer members were HIV infected, and, as a result, a more concerted effort was made to bracket professionalized forms of expertise. Often this issue arose when members of the group, generally health professionals, suggested that the publication should simply track and summarize developments in allopathic medications rather than address topics that HIV positive members felt were important like complementary medicine or the experiences of people with HIV/AIDS who are making informed health care decisions.

Making each project by and for people with HIV/AIDS could also be seen in the way each issue was produced. The two groups considered themselves to be collectives, each person

having an equal opportunity to contribute to the publication. Members generally had a preferred role as part of the group, writing over editing, for instance, but as much as possible, decisions regarding the planning, writing and editing of each issue were made by consensus. There was also an implicit expectation that everyone should be involved in all aspects of the production process: the planning, writing, editing, layout, printing, and evaluation of each issue.

The actual work involved, as a result, tended to be loosely structured and time consuming. There were advantages and disadvantages to this approach. On the plus side, the group meetings were often enjoyable social events. Talk would be as much about friends, ideas, medications, and local gossip than about the immediate task of producing the next issue. At *The Positive Side* most members were friends and HIV positive so this atmosphere tended to flow more naturally from the group. At the *Treatment Information Flash*, though, this type of environment emerged more gradually as the group became more familiar with each other. This atmosphere, I believe, helped to give those HIV positive members more opportunity to voice their ideas and views, and contribute to the publication in a way that they felt was safe and nonjudgemental. The difficulty of this approach was it often created problems in co-ordinating the different tasks, endless delays, and a long trail of missed deadlines. On occasion, often out of frustration, members of the group who were health professionals or staff of the sponsoring organization would try to make the process more formal, business like, and structured. However, this generally had the effect of either silencing or angering those who were at the group as people with HIV/AIDS and had an investment in keeping the process collective and informal.

At the level of representation, community-based meant that the material contained in the publications was, ideally, shaped and informed by the experiences of those living with HIV/AIDS. This perspective, it was assumed, enabled contributors to select topics, provide insight into health management, and present material in a way that was relevant to the needs, concerns, and lives of people with HIV/AIDS. Working toward this goal occurred in several ways. Language, for instance, was a constant source of debate as members struggled to distill medical information into a form that a person with a high school diploma or less would be able to understand and also hopefully enjoy reading. At least once every issue a person would be asked to edit or re-edit an article in order to make it more comprehensible but not any more complex or less interesting. At *The Positive Side*, one member was notorious for writing long in-depth articles which were valuable, to be sure, but for most people almost incomprehensible. Once submitted the other members would take turns trying to transform this information, often successfully, into the kind of language that people use on the street during the course of their everyday life. One of the rumours among members of *The Positive Side* collective was that CATIE had purchased a computer program that could automatically and instantly turn complex language into a form that a person with a grade four education could understand.

The diversity of people with HIV/AIDS and the varying social contexts in which they live was another issue that the two groups struggled with when trying to remain community-based media. Often medical information ignores the particular needs of women, gay men, people from different ethnocultural backgrounds, injection drug users, and so on. In acting as representatives of the HIV/AIDS community, group members (some more than others) were

aware that the information needs of different people with HIV/AIDS had been ignored and tried to redress this in the types of material that was covered (women's health) and the voices from the HIV/AIDS community that were included in the publications (personal accounts from injection drug users or aboriginal men and women). Trying to be community-based, then, meant using the lived experience of HIV/AIDS as a tool to both transform health information produced by medical science, the health care system, and the government, and to fill the information gaps (complementary therapies, for instance) left by or created by institutional discourses on how to manage HIV infection.

To sum up, it is evident that the meaning of community-based for those involved in both groups hinged on the extent to which people with HIV/AIDS could participate in the two projects and the extent to which their views and perspectives were seen as legitimate and essential to assist others to make informed decisions about their health care. In terms of the previous work on this issue, there are two main points to be made from this discussion. The first is that for those involved in these projects, creating and sustaining a project that conforms to what they considered to be based on a peer model of communication was not straightforward or simple but often ambiguous and involving negotiation, not only in terms of institutional forces, but between members working on the same project. The second point is that this process of negotiation and even conflict, occurred on several levels. Often it assumed that the struggle over self representation occurred primarily at the level of meaning and discourse, and secondarily at the level of production. This analysis suggests that there can also be an organizational level, as was the case with *The Positive Side* and the *Treatment Information Flash*, that has a significant influence over the extent to which a publication is

considered to be or defined as community based by those producing or consuming it. In fact, it is often the case that the way in which a publication is produced, and the material that is contained in that publication is framed by some type of organizational sponsorship because it is at this level that media projects receive the resources necessary for their continued survival.

The Limits of Print Media

In the introduction to *Surviving and Thriving with AIDS*, an early guide to living with the disease, Callen (1987: 45) explains why so much attention is devoted to health care: "whenever people with HIV/AIDS get together, talk always turns to treatments. And when we are done talking about treatments, we talk about treatments some more." When this was written in 1987, there were few treatment information resources available. People with HIV/AIDS relied on word of mouth, and on the handful of treatment publications just beginning to be produced at this time. Currently, treatment information resources abound. CATIE, for instance, has become one of largest AIDS organizations in Canada and is dedicated solely to collecting and providing information about health care and HIV infection across Canada.

Advancements in the provision of information can be attributed to the rise of treatment activism in the late 1980s and 1990s. This aspect of the AIDS movement has not only addressed issues of advocacy, but also devoted resources and energy to support and education programs for people living with HIV/AIDS. Over the course of this activism, treatment information has been provided in a number of different ways: through social

networks, publications, the fax and the phone, and the internet. *The Positive Side* and the *Treatment Information Flash* provide an opportunity to look at the role that print media projects have played in ongoing attempts to create forums for health care information about managing HIV/AIDS.

When looking back over the past fifteen years, treatment publications like *The Positive Side* and the *Treatment Information Flash* are best understood as transitional projects. They arose in response to the neglected information needs of people living with HIV/AIDS in the later 1980s and early 1990s. A myriad of like-minded projects arose in the late 1980s and early 1990s in communities across North America. Generally speaking, they were conceived of and produced by small groups of people infected and affected by HIV/AIDS, usually volunteers for an AIDS service organization, endeavouring to help others and to help themselves. In most cases, similar strategies of representation are used to convey information and opinions about managing HIV infection - a combination of lay investigative journalism and personal accounts and testimonials, always written from an empowered and positive perspective.

Of these projects there have been several successes. *POZ*, for instance, recently had an article reviewing the top eighteen AIDS treatment publications. Increasingly, though, the use of small scale print media to produce treatment information is in decline. In fact, for the eighteen successful publications reviewed in *POZ*, I would suspect that there have been hundreds that are no longer being produced. [19] In the 1990s greater attention has been devoted to developing more effective strategies for providing information about managing HIV infection. Gradually, with increased funding, treatment information organizations like

Project Inform and CATIE have started to use new media technologies like the phone, fax, and Internet as an adjunct to print media.

This new approach is seen to have several advantages, mostly connected to the idea that new media technologies are seen to be more consumer driven and interactive. One of the issues that plagued those involved in *The Positive Side* and the *Treatment Information Flash* was not knowing if the information that they were providing was what people with HIV/AIDS were interested in receiving and if they found the information useful when making health care decisions. Using electronic media, a person with HIV/AIDS can call, fax, or e-mail for specific information, rather than looking it up or waiting for it to be covered in a treatment publication. In addition, people living with HIV/AIDS are able to talk directly to another person about the treatment options that they are using or considering and discuss the potential advantages and disadvantages. Rather than simply receiving information, they are able to tap the knowledge of the person they are talking to about that information. In other words, speaking adds another dimension to the process of learning about how to make informed decisions about managing HIV infection. Also, from an organizational point of view, new media technologies provide a new means of collecting information about treatments and tracking the types of information that people living with HIV/AIDS were requesting. In the case of complementary therapies, for instance, CATIE is now able to receive information about new treatments that people are trying when they call in for information. And, they are able to identify what the demand is for information about particular complementary therapies (broken down by gender, ethnicity, sexuality, geography and so on) based on the calls that they receive from people living with HIV/AIDS locally and nationally. Even though the

accuracy of this measure can be questioned, it does provide a guide for making decisions regarding the allocation of resources and the development of programs and services.

It would be inaccurate to say that this shift in the provision of treatment information is a rejection of print media or print media projects like *The Positive Side* and the *Treatment Information Flash*. There is a lineage between the two different approaches. First, with the use of new media technologies, AIDS organizations have kept and embraced a peer model of communication that has been central to the PWA movement and to PWA print media like treatment publications. CATIE, for instance, has in place a peer treatment counsellor training program in which people with HIV/AIDS advise and assist those who request information. Part of this program includes helping organizations across Canada train their own peer treatment counsellors, as was the case at the Hamilton AIDS Network. Acquiring counselling and computer skills, documenting treatment information, and talking to other people living with HIV/AIDS is thought to be a more valuable and meaningful form of involvement and participation for people with HIV/AIDS than, for instance, contributing to or producing a treatment publication. However, it should be noted that prior projects that struggled to sustain a community-based or peer model of communication were influential in the development of this current approach to providing AIDS treatment information.

A second example of this lineage can been seen in the way that the turn to electronic media has not involved a rejection of print media, but instead, has been a way of emphasizing speech over print as the primary means of conveying information about managing HIV infection. Speech via the phone means that print is placed within a multi-media context. Treatment counsellors, for instance, still rely on print media for information, although

organizations like the Network have chosen is to subscribe to institutionally produced media (medical journals) over community-based media (PWA organization newsletters and other AIDS publications). Guiding people with HIV/AIDS through this information can be done through print (there are fact sheets available) but it is usually done through conversations with peer treatment counsellors.

The reliance on speech over print may be a response to the complexity, abundance, and ambiguity of current allopathic and complementary approaches to treating HIV infection. McLuhan (1964), for instance, has argued that new types of media emerge and predominate when societies increase in scope and complexity. In *Understanding Media*, he argues that there has been an evolution of media - from speech to print to electronic - as Western industrial societies have become more complex and more global. The dominance of electronic media, for McLuhan, was a return to speech and a move toward turning the world into a global village. On a more localized and specific basis, the provision of treatment information has followed a similar pattern - from small localized networks (speech), to treatment publications (print), to the use of fax, video, telephone, and the internet (electronic). For a generation of youth who have grown up with visual media rather than print, for instance, it makes sense to provide complex information about health care in a more familiar video format. In the case of treatment specific AIDS organizations, the approach is less oriented towards privileging electronic media, but instead, trying to effectively integrate speech and print through new media technologies like the Internet. [20]

Print media projects like *The Positive Side* and the *Treatment Information Flash* have limitations as effective ways of providing treatment information. However, they have played

an important role in bridging the early social networks of people talking about treatments before there were any mediated forums to the current state of affairs in which there are social networks, publications, hotlines, treatment counsellors and web sites all under the governance of AIDS service organizations. In particular, such small scale grassroots projects proved that it was possible and essential that people with HIV/AIDS be involved in and have control of (as much as possible) the production and distribution of information about managing HIV infection. Currently, there are fewer opportunities for people with HIV/AIDS to start their own print media projects; however, there are greater opportunities for people with HIV/AIDS to become involved in providing information, for instance, as treatment counsellors.

Conclusion

Based on the analysis in this chapter, it is evident that the production of treatment information has changed dramatically over the course of the AIDS epidemic. Using two print media projects as case studies, *The Positive Side* and the *Treatment Information Flash*, I have tried to make several points about the efforts that have occurred throughout the AIDS movement to create public forums about health care and HIV/AIDS. First, forums for treatment information would not have been possible without the rise of treatment activism in the late 1980s and early 1990s. This organizing among people with HIV/AIDS not only put pressure on power structures that posed barriers to treatment access, it also provided the political will, ideological guidance, and practical resources needed to create programs and services directed at educating and supporting people with HIV/AIDS in regard to having the opportunities to make informed decisions about their health.

A second important point in this chapter is that treatment information projects like *The Positive Side* and the *Treatment Information Flash* have played a pivotal role in creating an alternative public sphere about how to become actively involved in managing HIV infection. In particular, they established the idea of a peer model of communication as an effective and viable way of sharing health information and viewpoints among people with HIV/AIDS. Such efforts have helped to make it possible for people with HIV/AIDS to be more actively involved in the community-based response to HIV/AIDS. Also, the struggles of those involved in print media projects led the way to the development of new, more advanced and institutionalized approaches to the provision of treatment information. As a result, even though *The Positive Side* and the *Treatment Information Flash* are no longer in existence, their legacies can be seen in the ways in which CATIE and the Hamilton AIDS Network use treatment counsellors to provide information through the phone, in print, by fax and through the Internet.

An instructive way to close this chapter is by looking at the current state of treatment activism and its role in sustaining an alternative public sphere about health care for people with HIV/AIDS. It is evident that AIDS activists have been successful in securing resources from government and industries in order to create treatment information forums like CATIE. However, an argument can be made that with the attention that has been devoted to developing an infrastructure for treatment information, other aspects of treatment activism have been neglected. It is likely that government is far more interested in funding a treatment information resource than it is in taking an aggressive stance toward regulating pharmaceutical companies or developing strategies or putting resources toward making

treatments available and affordable to people with HIV/AIDS. As a result, people with HIV/AIDS have access to an extensive body of knowledge about the latest AIDS treatments but have great difficulty gaining access to these treatments.

In a related vein, a second issue for treatment activists is that as AIDS organizations make closer ties to dominant social institutions, there is always the question of whether this will limit the extent to which they can exert the radical politics that are needed to advocate on behalf of people with HIV/AIDS who continue to be marginalized or oppressed. As many AIDS organizers have noted for many years the situation globally for people with HIV/AIDS regarding access to not only information about treatments but any form of medical treatment continues to be grossly neglected by those in positions of power and or those who have the means available necessary to redress this situation. *The Positive Side* and the *Treatment Information Flash* are examples of organizing by and for people with HIV/AIDS in response to perceived injustices on the part of the government, the health care system, the AIDS industries, and the AIDS movement itself (though to much lesser degree). It is possible that, for instance, the training involved in becoming a peer treatment counsellor will engender similar forms of organizing by and for people with HIV/AIDS. At the same time, it is also possible that new forms of communication will serve to further isolate and individualize those who are seeking information about how to manage HIV infection.

Just as there was uncertainty as to what might result from the formation of groups like ACT UP and AIDS ACTION NOW! in the late 1980s when angry members of HIV/AIDS community decided to adopt more radical political steps in an attempt to make governments and industries respond to the AIDS epidemic, there is uncertainty now about what will result

from this current more institutionalized approach to treatment activism within the AIDS movement. At a time when the climate around the treatment of HIV/AIDS is particularly optimistic there is always the danger of overlooking the issues and problems that people with HIV/AIDS continue to face in terms of their health care. Unlike ten years ago, there are now communication channels in place for people with HIV/AIDS to share knowledge and experiences about making informed health care decisions and taking action in order to gain control over the means to health. It will be interesting in the coming years to see how this alternative public sphere is used and how it is transformed.

FOOTNOTES

1. I am indebted to those involved in these projects for their insight, their willingness, and their help with this project.

2. I have mentioned several times that there has been very little written on the PWA self empowerment movement. Interestingly, the recent work on treatment activism could arguably be considered to be about the PWA movement. The authors, however, have chosen to emphasize the involvement of people with HIV/AIDS in organizing specifically around treatments as opposed to their involvement in political organizing in general. Perhaps this work on treatments will serve as the basis for research on other aspects of the PWA movement.

3. Based on my reading of PWA media, there is still a debate among those involved in the organized AIDS community regarding the role of ACT UP as part of the AIDS movement. On one hand, some argue that it is important to define early forms of organizing as representing the start of AIDS activism. On the other hand, the case is made that ACT UP in fact marked the point at which the AIDS movement came into fruition as a political force both in terms of generating large scale interest in AIDS organizing and having influence the power structures that controlled public policy regarding HIV/AIDS. My own perspective is that there is not much use in privileging ACT UP or other early forms of PWA organizing as marking the start of the AIDS movement. Instead, it is more instructive to define each as aspects of AIDS activism and focus on the inter-relationship between direct action groups and other forms of AIDS organizing.

4. In many respects the tendency to ignore the early AIDS movement highlights the value of PWA media from this period. Newsletters, for instance, document the activism among people with HIV/AIDS prior to high profile groups like ACT UP and AIDS ACTION NOW!

5. It should be noted that even as only one part of a broader treatment activism the actions of groups like ACT UP have been a central if not leading component of this struggle.

6. It is not my intent to pit different types of activism against each other. In practice, education, support, advocacy, and research regarding health care for people living with HIV/AIDS are interconnected within the community-based AIDS movement much more than they are separate entities. For instance, organizations like the PWA Health Group and ACT UP, although dealing with different aspects of health care, have informed and influenced each other. In other instances, like in Vancouver, a range of treatment and health care programs and services are provided by a single PWA service organization (or closely linked network of organizations). In other words, though treatment activism has taken a variety of forms in regions across North America it is still part of the same broader community-based AIDS movement.

7. One of the first individuals to go public through the media as a person with AIDS wore a pin that stated, "stay informed." Since that time this slogan has been taken up as a goal to work toward within the PWA movement.

8. *AIDS Treatment News* is also a good example of the influence of the gay press on the development of PWA media. Involvement in gay print media provided John St. James with the guidance, skills, and resources needed to create a publication about AIDS treatments.

9. The Montreal Manifesto states in its list of demands that "a multi-national, international data bank with medical information related to HIV disease must be created. This includes all data concerning drugs and treatments, especially basic bio-medical research and the initiation and progress of clinical trials.

10. Though CATIE became an independent organization it still remained closely connected to the work of AIDS ACTION NOW! In fact they are still located in the same offices, though AAN! has faded as CATIE has grown in scope and size. The influence of changing politics within the community-based response to AIDS on the relationship between these two groups would be an interesting topic for future research.

11. It appears that during this time of restructuring there were several people with CATIE who felt that the unscientific and dubious reputations of many complementary therapies posed too much of a risk for the organization when trying to provide reliable and standardized information about managing health. Information about complementary therapies was integrated into CATIE but in a controlled and careful way. According to some respondents, there simply was not enough people in the organization who could advocate for the continuation of *The Positive Side* as a forum for complementary therapies.

12. Even though I was at the meeting, the decision was made in such a muted way that I had to call and ask another member of the group whether or not we were in fact going to get together for another meeting.

13. It is thought that people move to large urban centres for several reasons. First, there are a broader range of services and a more organized HIV/AIDS community. Second, living in a new and more populated place offers a measure of anonymity which can be a relief from the stigma of being HIV positive. And third, more regional settings tend to be, generally speaking, less supportive of political organizing among marginalized or oppressed groups.

14. Several people have argued that it was the Network's unsupportive and unresponsive approach to the needs and concerns of people with HIV/AIDS that contributed to the failure of previous attempts at organizing by and for people with HIV/AIDS. While it is unlikely that that was the deciding factor, it is arguable that the Network did little to help facilitate community mobilization and development.

15. It is interesting that the group of people with HIV/AIDS in Hamilton would consistently start their organizing efforts through the creation of a publication. Similarly, when the PWA movement first began, people with HIV/AIDS were also interested in starting their own media projects in association with their political organizing. This use of media suggests that there is a relationship between seeking political representation (having a voice in the AIDS movement and AIDS policy) and self representation (having a voice in the social construction of HIV/AIDS). The desire for self representation may also have been particularly strong among people with HIV/AIDS given the extent to which they have been misrepresented in the media and in official discourse about the HIV/AIDS epidemic. This connection is also likely contextual. For instance, in the case of the media project at the Network an argument can be made that developing an autonomous publication was a means of containing the political involvement of people with HIV/AIDS in the organization. However, media projects developed as part of the early PWA movement, in New York or Vancouver, seemed to be more closely tied to declaring publicly that people with HIV/AIDS had achieved and were working toward political representation in the AIDS movement.

16. What happened with the publication is one volunteer had taken control of its production and became increasingly unwilling to let anyone else become involved. Also, the content began to only reflect this person's own interests only rather than the interests and concerns of local people with HIV/AIDS.

17. Noam Chomski's work on the manufacture of consent can be seen as an example of such well intended but top down Leftist media projects. This work falls into the Marxist dilemma of false consciousness in which the masses have been misinformed - primarily through the media - to the extent that they are no longer able to see injustice or oppression in their own lives or globally. There are moral overtones regarding what exactly citizens should or should not be prioritizing in their lives as political or significant.

18. It was suggested that with an increasingly diverse cross section of people with HIV/AIDS it no longer makes sense to talk about an HIV/AIDS community. Instead, it is more likely that there are several HIV/AIDS communities - gay men, women, people of colour, injection drug users. Others have gone even further suggesting that the idea of an HIV/AIDS community is false, that there are only loosely connected different groups of people who really have no unifying common identity from which to build a sense of community. It may be possible to talk about a community of gay men with HIV/AIDS but perhaps less accurate to talk about a community of children with HIV/AIDS because they do not have a single shared collective identity. Both reasons were given as possible explanations as to why there was such sparse response to the publications by readers over the course of their production and distribution.

19. An argument can also be made that those eighteen publications reviewed by *POZ* have come to be seen as large scale and legitimate sources for community-based information about treatment. As a result, there has been a trend towards placing less priority on creating

localized projects like *The Positive Side* and the *Treatment Information Flash* because they would only be duplicating services that are already available in abundance in a much more legitimate and elaborate format.

20. The decline of print as the dominant form of communications supports McLuhan's view in the 1960s that electronic media would transform the way in which people interact and think about their social worlds. However, rather than a rejection of speech or print, this electronic era has instead reconfigured our relationship to such means of communication. Recently, with the development of new technologies like the Internet, there have been some interesting social trends that suggest we are entering into a post-electric era. For instance, through electronic mail some people are returning to the use of print and writing, rather than speech as a preferred means of communication. Also, the panic created regarding the rise of a society dominated by electronic media has caused a kind of backlash in which many people are returning to print, particularly with their children, as an essential but increasingly lost form of communication.

CHAPTER SEVEN: GENERAL INTEREST MAGAZINES

On one level, print media by and for people with HIV/AIDS are designed to be a practical resource. They often include a listing of community services, updates on treatments, guides to interpreting medical results, and even legal advice related to living with HIV/AIDS. However, print media by people with HIV/AIDS are not purely pragmatic ventures. Such projects are also about the struggle for self representation or what has been referred to as giving HIV/AIDS a human face. In a recent issue of *POZ* magazine, for instance, Andrew Johnson writes: "I have been HIV+ for three years and I am sick and tired of people, society and scientists telling me I am going to die. Many of us are living fulfilling lives in spite of HIV. I have hope and I have just begun to live." This account provides a glimpse of how people with HIV/AIDS have tried to reclaim and transform the meaning of HIV/AIDS. Contesting what it means to be a person with HIV/AIDS has been a key component of the PWA movement. Subsequently, it is also a prominent theme in PWA media. How people with HIV/AIDS have been represented in two such media projects, *POZ* and *Diseased Pariah News* (*DPN*) is the focus of this chapter.

Hegemony and the Lives of People with HIV/AIDS

Popular or common sense understandings of HIV/AIDS are constructed, legitimated and disseminated through discourses of social institutions like the state, the medical establishment,

the mass media and the education system. This hegemonic meaning of disease often appears

to be fixed in biology or in medical science. However, as Treichler (1987) as argued, AIDS

is a social construction; its meaning is always fragmentary, open to interpretation,

denunciation, and transformation:

> the very nature of AIDS is constructed through language and in particular through
> the discourses of medicine and science; this construction is 'true' or 'real' only in
> certain and specific ways - for example, insofar as it successfully guides research or
> facilitates clinical control over the illness.

Treichler continues to examine how the medical and scientific constructions of HIV/AIDS

have been problematic in that they have served to oppress gay men and women by "guiding

research about the disease" and "facilitating clinical control of people with HIV/AIDS." At

the same time, hegemony is also expansive in the sense that the medical establishment, for

instance, is engaged in a project of furthering knowledge and expertise in order to control and

eradicate disease. However, this control is dependent on the exclusion and subordination of

those directly infected and affected by HIV/AIDS. It is this hegemonic project that has been

contested by AIDS activists and has, as result, remained uncertain.

With regards to the mass media, Watney (1987) has made similar arguments regarding

the ways in which gay men with HIV/AIDS have been represented. Early in the epidemic, for

instance, the media contributed to a vast moral panic regarding the threat that people with

HIV/AIDS - as immoral, infectious, and unnatural - pose to the general (heterosexual) public.

Furthermore, as Crawford (1994) notes, the media also constructed certain people with

HIV/AIDS - gay men, drugs users and ethnic minorities - as 'deserving' their infection

because of their "deviant" lifestyles. Such perceived transgressions of middle class values had

both religious and secular forms; in the latter, people with HIV/AIDS were punished for indulging in high risk behavior whereas in the former, people with HIV/AIDS were being punished by god for their sins. This critical work on AIDS discourses argues that the state, medicine and the media have over the course of the epidemic sustained an understanding of HIV/AIDS that disregards the rights, needs and concerns of those who are living with the disease.

It is true that scholars like Watney and Treichler have provided a strong critique of hegemony as it pertains to HIV/AIDS. However, much of this work has tried to emphasize how it is possible to transform symbolic forms of oppression . In the case of HIV/AIDS, it is evident that over the past fifteen years, institutional representations have become more sensitive and responsive to the lives of those who are infected with HIV/AIDS. For instance, in a North American context, it is no longer as common to see HIV/AIDS represented as a gay disease or to see people with HIV/AIDS portrayed as inherently immoral or untouchable. [1] This transformation has come because those infected and affected by HIV/AIDS have collectively struggled to redefine the meaning of HIV/AIDS. Efforts to reconstruct the meaning of HIV/AIDS is not a rejection of hegemony but a process of appropriating and transforming hegemonic constructions that are consistent with the emancipatory project of people with HIV/AIDS.

Counter Hegemony and the AIDS Movement

The AIDS movement has been concerned with how dominant understanding of HIV/AIDS have created a negative social climate for those infected. A key strategy in

responding to this hegemony has been to encourage people with HIV/AIDS to create their own supportive and helpful understandings of the disease, particularly by contesting common misrepresentations about what it means to be a persons living with HIV/AIDS. In speaking out, activists and organizers have attacked and tried to influence officially sanctioned meanings about people with HIV/AIDS.

Print media projects like *DPN* and *POZ* have been one means through which the PWA movement has worked to transform the meaning of HIV/AIDS. *DPN* and *POZ* are not typical of the earlier forms of PWA media discussed in previous chapters. They are not newsletters or treatment updates nor are they formally associated with an AIDS organization. Instead, they are representative of media projects by and for people with HIV/AIDS that arose as a result of a resurgence in AIDS activism during the late 1980s and early 1990. In other words, *DPN* and *POZ* are more closely aligned with political advocacy groups like ACT UP or the Treatment Action Group (TAG) than they are with PWA organizations like the PWA Coalition of New York or Body Positive. While the political roots of the two are quite similar, they are very distinct media projects.

DPN is based in San Francisco. It was started by three HIVers (their term for people living with HIV/AIDS) as an extension of their common interests in publishing, the AIDS movement, gay sexuality and living with HIV/AIDS. The editors of the publication describe it as a high quality zine. Zines are produced independently via desk top publishing and are intended as an alternative to mainstream glossy magazines like *Vanity Fair* or *Time* ('zine' is a shortened form of magazine and they are also usually half the size of a magazine). The

editors at *DPN* often parody and subvert the conventions of mainstream magazine publishing through the use of mock advertisements.

DPN's focus is mostly the humorous and satirical side of HIV/AIDS as understood by HIV infected gay men who are politically informed and sexuality liberated:

> *Diseased Pariah News* is a self-indulgent publication of, by and for people with HIV disease (and their friends and loved ones). We are a forum for infected people to share their thoughts, feelings, art, writing, and brownie recipes in an atmosphere free of teddy bears, magic rocks and seronegative guilt.

The editors at *DPN* sought to create a form of social support that encouraged an aggressive approach to living with HIV/AIDS. They often felt that support services for people with HIV/AIDS encouraged passivity or victimhood and were more about the needs of those who sought to give support rather than the needs of those who were receiving support. And, as they said, "what we are hoping to do is bring some much needed levity to the experience of HIV infection."

POZ is located on the opposite coast in New York. The magazine was founded by Sean Strubb, an HIV infected gay man who has, in creating *POZ*, twinned his business, Strubco Industries, which is primarily a mail order marketing business, with his involvement in AIDS organizing and activism on a local and national level. *POZ* and Strubco have becoming increasingly separate entities as the magazine has grown in scope. [2] It is as far as I know the first for-profit publication by and for people living with HIV/AIDS.

Interestingly, *POZ* parodies and emulates mainstream glossy magazines. As a glossy lifestyle magazine, *POZ* looks and reads like any of a number of magazines available to the

general public. In subscription notices, for instance, the editors are fond of quoting reviews

of the magazine:

> *POZ* has been called 'easily as plush as *Vanity Fair*' by Frank Rich of *The New York
> Times*, 'literate and provocative' by *The Los Angeles Times*, 'powerful, courageous
> and beautifully written' by Liz Smith, '(having) larger-than-life influence,' by *Adweek*
> and an 'extraordinarily well-written, meticulously crafted periodical' by the *Utne
> Reader*.

At the same time as taking pride in producing a 'high quality' magazine, there is also a

political agenda which is claimed to be the base of this for-profit tactic. In making *POZ*

mainstream, Strubb has tried to use the veil of a glossy magazine to promote what the

magazine industry and the general public would consider to be subversive material. As one

reader pointed out in a letter,

> your magazine is very informative and has kept me up to date on the ever-changing
> world of the AIDS epidemic. However, here in the Bible Belt, I have found that it
> has been offensive to some people. .. Do you think you could tone it down so it can
> reach all people and not just one group?

In addition, *POZ* has been banned on several occasions from newsstands in the United States.

It would appear that for some, a successful glossy lifestyle magazine should not be about the

lives of those who have a stigmatized and life threatening disease.

The political edge of *POZ*, then, is to use a dominant media form to advance the needs

and interests of a marginalized and oppressed community. Despite the for-profit status, the

magazine is said to be first and foremost about giving people with HIV/AIDS the information

they need to survive:

> *POZ* was founded primarily to get information to HIV positive persons for whom
> it could extend or improve the quality of their lives. Since the first days of the
> epidemic, access to information was key to survival. We also want to create a
> common media context between fulltime treatment activists — the extraordinarily

empowered patient — and those impacted by HIV who are not going to read the technical newsletters and attend meetings.

In talking to people involved in producing publications by and for people with HIV/AIDS, many question *POZ* as a legitimate expression of those infected and affected by the AIDS epidemic (though this did not prevent them from reading the magazine on a regular basis). However, based on *POZ*'s mandate, it would appear that such misgivings are based on the form that the magazine has taken rather than its message. [3]

It is clear that *POZ* and *DPN* are very different publications. Nonetheless, as products of the PWA movement, they are committed to the same set of principles regarding need to promote self empowerment among people living with HIV/AIDS.

> Language is important. It influences how society, politicians and health care providers view people with AIDS. Most importantly, it influences how we view ourselves. If we believe ourselves to be 'terminally ill,' then we void everything else about our lives. Our love, passion, vision and vitality. Our hopes and dreams. We might as well just plan the funeral and wait to die. *POZ* delivers the possibility of survival in an inspiring, hopeful manner.

This excerpt is from *POZ*'s mission statement but it could equally be applied to *DPN*. Both publications are about constructing a version of living with HIV/AIDS that challenges 'official' AIDS discourse in order to support and educate those who are trying to figure out what it means to be HIV positive.

In this sense, as media projects that are counter hegemonic, *POZ* and *DPN* challenge dominant understanding of HIV/AIDS by constructing a PWA collective identity. The concept of collective identity has recently been revived in order to make sense of the cultural dimensions of contemporary social movements. [4] It is beyond the scope of this paper to address the current debate in social movement theory regarding the concept of collective

identity. My use of collective identity is informed by the work of Melucci (1989) who defines

it simply as the "we" feeling that is felt and expressed by those involved in new social

movements. Melucci argues that this sense of inclusion and solidarity is a social process,

negotiated and sustained through the social networks required for political organizing. It is

possible, though, to extend the concept beyond social interaction to include media

representations. Media projects like *DPN* and *POZ* represent what it means for people to

understand themselves as 'living with HIV/AIDS' and not dying of HIV/AIDS. In portraying

collective identities, publications are intentionally prescriptive: they are symbolic resources

for communities impacted by the AIDS epidemic; and they challenge and reconstruct

dominant hegemonic understandings of what it means to be a person with HIV/AIDS.

Collective Identity Frames

In constructing a collective identity - what it means to be a person living with HIV/AIDS -

DPN and *POZ* draw on the images and writing of those who are HIV infected and affected.

Unlike official AIDS discourse, it is tempting to read such representations as authentic or

telling the "truth" about HIV/AIDS. On one level, it is possible to argue that the version of

HIV/AIDS presented in *DPN* and *POZ* is more accurate or grounded than, for example, a

story in a tabloid about AIDS because it has been created by and for people with HIV/AIDS.

At the same time, it is important to realize that the meanings conveyed in PWA media projects

are still nonetheless ideological; they are written from the perspective of those involved in the

organized AIDS movement. For instance, one of the ideological prerequisites for the PWA

movement in constructing a collective identity is managing or negotiating differences between

people with HIV/AIDS. It is necessary to allow for the expression of difference but not at the expense of a larger sense of solidarity as people with HIV/AIDS.

When examining the profiles, articles, editorials, advice, and images in *DPN* and *POZ*, it became apparent that there were several recurrent frames of reference used to represent what it meant to be a person with HIV/AIDS. The first is living with HIV/AIDS. The second is surviving HIV/AIDS. And the third is belonging to an HIV/AIDS community. Within each frame of reference there were several recurrent subthemes. My analysis of how the PWA movement has represented a collective identity through media projects like *DPN* and *POZ* is organized around these three frames.

Living

People with HIV/AIDS are increasingly, though not entirely, being perceived as having a chronic and manageable condition. This shift away from understanding HIV/AIDS as a terminal disease has been gradual. In fact, for much of the past fifteen years HIV infection has been viewed as a death sentence. For instance, in the mass media, more so early in the epidemic than in recent years, people with HIV/AIDS were portrayed as if they were sick and dying. [5] Similarly, in medical discourse, HIV/AIDS has been for many years narrowly defined as a terminal disease. AIDS patients were, and in many cases still are, treated as highly infectious and terminally ill.

Contesting this definition of HIV/AIDS, because of its negative impact on those infected, has been at the centre of efforts within the PWA movement. In constructing a collective identity this has meant representing people with HIV/AIDS as living rather than dying. This

emphasis on living has been a dominant frame of reference in *POZ* and *DPN*. I have selected

a series of recurrent themes or narratives from *DPN* and *POZ* that relate directly to people

writing about themselves as living: stories about being diagnosed, about being ordinary yet

extraordinary and about disclosing one's HIV status. They are not mutually exclusive or

exhaustive. The general sentiment expressed is that HIV/AIDS may be life threatening and

likely fatal but that does not mean people with HIV/AIDS need to, or even should have to,

understand themselves as dying.

Diagnosis

Stories about being diagnosed is the first theme. Recalling this experience, or set of

experiences, is a focal point for many of the personal accounts that appear in *POZ* and *DPN*.

Often, although not always, a similar pattern was evident in these stories. For instance,

regardless of whether a positive HIV test was anticipated or completely unexpected, receiving

the official diagnosis was described as a traumatic and pivotal moment. Taking the 'test' was

often a form of self examination - passing or failing depended on what results were

anticipated. It was an institutional confirmation of one's identity as infected. Many people met

this new knowledge with a combination of fatalism, fear, and denial. For instance, in *DPN*,

Rondo Miecckowski recalled that he was,

> on the phone with the clinic. The counselor says, "Well, you're positive." Blood
> rushed up from my gut - my face hot. Like ice it burns. My stomach shrinks,
> contracts. I'm disappearing like Alice, getting tinier and tinier because she ate the
> wrong thing. I figured I would be positive. I knew it. I had sex with guys who were
> now dead. Enough of them. Who isn't positive these days? But, to actually hear it -
> was something else. After finding out - after this revolution - that the rest of my life

was going to be different from now on, forever and ever, my first thought was worthy of a queen: "Well, *now*, I am never going to see Paris."

Similarly, in a forum on HIV and youth in *POZ*, one HIV positive teenager described her diagnosis in this way:

> I found out through my second pregnancy. This lady put me in a room, and she said I needed to sit down for this. She looks at the chart and says, 'you've got HIV.' I said, 'What?' Then she says, 'you heard me, you've got HIV.' So I went up on her and I threw all the shit off her desk. I tore down the whole place, and she was telling me to calm down. I was like 'you better get the fuck outta my way, lady.' I stormed out of her office and the hospital. It was on main street. This truck was coming and I got ready to just walk right out in front of it, I swear to God.

A positive HIV test was the focus of many accounts of being diagnosed. However, people with HIV/AIDS also described the subsequent impact that comes from being diagnosed again with numerous HIV-related opportunistic infections, and in some cases, with "full blown" AIDS. For instance, in suggesting the use of merit badges showing the degree of progression (for purposes of cruising or to make it easier when taking a medical history), Bodkin in *DPN* describes his own diagnosis history:

> A careful study of my merit badges would quickly reveal my obscenely low T-cell count (17 at last testing), the fact that I've had PCP, peripheral neuropathy, MAC, wasting syndrome, and that I have taken every nucleoside analogue known to man. This would allow those who want to fawn over me or avoid me to act accordingly, and avoid the frustration of mistaken acquaintanceship.

Bodkin's humour illustrates what was expressed in several articles, profiles, and stories: that encountering medical diagnoses and the medical tests measuring the progress of HIV/AIDS was an issue, at times difficult and traumatic, that those infected had to face on a continual basis.

In stories about diagnosis health care professionals often figure prominently because they deliver the news and are supposed to be there to help and, because they are representatives of medicine, the institution that devised these various diagnoses. Often, as was the case with this youth, the impact of dealing with health care professionals was negative:

> I heard about the Philadelphia Department of Health giving free STD testing, so one day after school I decided to go. The guy asked if I wanted an HIV test. 'Oh, sure' Here I am, 15 years old, and he does not take the time to explain what HIV is. So, about a month later, *they came to my house*. They buzzed our apartment. I lived on the third floor, so I looked out the window and saw this big, yellow truck. The first thing that came to mind is 'Death is coming to get me!' So my grandmother, who was about 67, comes downstairs and he tells her. I received no pre-test or post-test counseling. He didn't give me any resources. My grandmother told me that if I took some pills it would go away.

Not all encounters with physicians, social workers, or counselors were negative, though. Occasionally, people with HIV/AIDS wrote about how their physician, for instance, helped them to pause and consider their options upon hearing the news that they had seroconverted. [6] Or, a nurse who helped one HIVer, writing in *DPN*, when the difficulties of being diagnosed with "full blown" AIDS in hospital became too much to handle: "In the middle of a Night From Hell I was rescued by an angel from heaven, or the equivalent, a gentle dark Queen Nurse who laid his warm hands upon me and healed my weary soul. He took especial care of me till dawn and I could be released."

Facing a positive HIV test or an AIDS-defining illness is only part of the personal accounts of being diagnosis in *POZ* and *DPN*. After a diagnosis, in most cases, people completed their story by writing about how they came to overcome their feelings of panic, fear and despair and adopt a more constructive and hopeful understanding of their infection. In Mieckowski's story, for instance, this transformation came to him in a vision:

> I didn't know what to do. So I did what I always do when I don't know what to do. I went to bed. And then I had a vision. I saw a bull, galloping toward me. He got so close I could smell his rich hide. Suddenly, there was lots of blood - spilling, pouring, into a chalice - a cup full of bull's blood. That was it. I knew then - somehow I knew, dammit, that what I had to do - if I wanted to live - was to put on black leather (the bull), and heavy black boots (galloping toward me), to put on this armor, get out of bed and walk into the world.

Among accounts of diagnosis, receiving guidance through a vision was not a common route through which people came to think differently about their infection. Instead, many wrote about the influence of community resources, which was usually their participation in AIDS education and support programs. The profile of Jackson Myers in *POZ* is a good example of this type of scenario. Upon hearing that he was HIV positive, Myers "spun out of control - lost his job, developed psychological problems and turned to IV drug use." This downward spiral was reversed, according to Myers, when he became involved in Positive Voices, a choral group made up of twenty five people with HIV (which is part of Cathedral of Hope, the world's largest gay congregation). Myers wrote that singing has helped him to focus his life and his musical talents. As the director of the chorus, the message that the group tries to convey is an extension of Myer's own beliefs about being HIV positive:

> Positive Voices wants to present people who are living positively with HIV. All of the music we do is centred on themes of hope, strength, courage, and faith. We want people to see us and hear our music and hopefully get the message that they don't have to live with the despair that HIV can bring.

Involvement in political activism was also often cited as a means through which people came to embrace life and reject the idea that their diagnosis was a death sentence. For instance, as John Iverson notes in his profile in *POZ*, "I got involved in the fight against AIDS to save my

life. If I am not trying to make a better world through social change then I am basically wasting my life on this planet. That's sort of my very own religion."

People came to different conclusions in their writing about making sense of an AIDS diagnosis or a positive HIV test. In other words, what it meant to become a person living with HIV/AIDS varied. There were those profiled in *POZ*, for instance, who came to view their diagnosis as life affirming, as an opportunity to change, or even as a gift. In a profile of Marcus Wayland, for instance, he claims that "HIV infection has given me time to stop being false, to strip away all the shit and appreciate things. It has been a really thoughtful time. A long life is not important to me. What is important is getting at the root of what is torturing me." Another person with HIV/AIDS similarly wrote,

> An HIV diagnosis has led many of us to embrace life more consciously. Without expecting Hallmark style peace and joy, we can bring this same approach to the winter holidays and enjoy their pleasures. All we have to do is share and honor our true selves.

In contrast to this view, the editors at *DPN* started their zine to counter what they perceived to be an overly positive and unrealistic portrait of HIV: "We should warn you that our editorial policy does not include the concept that AIDS is a Wonderful Learning Opportunity and Spiritual Gift From Above. We are just a couple of guys who ran into a Danger Penis and caught something we don't like very much." As a result of this more tempestuous approach, the stories and profiles in *DPN*, like this excerpt from Glenn Gaylord's reflections, tend to address both the hopeful and miserable side of living with HIV/AIDS. "When I think of AIDS," he writes,

> I think of the disappointment on faces when the lab work comes back… '*Not as we had hoped.*' I think of the people sitting at home as their lives close in on them.

Being alone. Being afraid. But sometimes, when I'm not concentrating to hard, I also think of the unbelievable courage. The ability of a man to proudly swim in a public pool covered with KS. But soon enough, I lose those warm and fuzzy feelings and the scary stuff bubbles back up to the surface. Thoughts of needles and hollow cheeks and shit-filled diapers. Of another day *without* a cure. And another day *without* hope. And then another *with* hope. And then another day goes by.

Regardless of differences in the meaning of an AIDS diagnosis such stories in general illustrate how it is possible to challenge an imposed medical identity, terminal AIDS patient for instance, and reject the idea that HIV/AIDS is a death sentence. However, such personal accounts also suggest that focusing on living and not dying is an ongoing and often difficult process for many people with HIV/AIDS.

Ordinary yet Extraordinary

The second predominant theme about "living with HIV/AIDS" is portraying the ordinary and extraordinary. At first, it may seem as if ordinary and extraordinary are contradictory. Yet, as this excerpt from an article in *POZ* illustrates, in portrayals of people with HIV/AIDS the two are often twinned: "Baseball, Hotdogs, Apple Pie and HIV. Eagle scout Henry Nicoles likes blondes, cars, and 'sex on the beach.' Talking with him you wonder: When does a normal young man in extraordinary circumstances become an extraordinary young man?" This question - how are people with HIV/AIDS both normal and exceptional - is frequently explored in *DPN* and *POZ*.

Representations of the ordinary often take the form of stories and profiles about everyday life: "In this issue of *POZ*, Magic Johnson talks about everyday life and HIV." In such

profiles, for instance, people (celebrities and the more anonymous) are frequently asked to

talk about their daily lives, particularly, as in this example, in reference to being HIV infected:

> Thinking about AIDS hasn't become a part of my daily routine - I will not let it. Every morning, my lover, roommate and I all gather at the breakfast table: I do the crossword puzzles, we watch the *Today* show, I go to work. The only time I think about AIDS is when I have to take my pills at night. Sometimes I'll even get into bed and then remember that I forgot to take my drugs.

Portrayals of the ordinary also look at people for whom HIV infection has had an impact on

their daily lives. In *DPN*, many of the personal accounts describe, in a matter-of-fact way,

how the unique or difficult aspects of HIV/AIDS become routine, or even mundane. For

instance, when a friend died one of the editors of *DPN* wrote:

> Darn. One of our editors is dead. The call came late this morning. I paused for some cold pizza, then hopped the bus to the Kasier hospital. When I reached the ward I looked in the room and saw the usual things. 'Tom' I said to myself, 'Your colour looks terrible! How did you get so jaundiced overnight?' I still hadn't caught on. ... Everybody had already gathered his things, except for the lonely looking oxiles plant. During a really bad night Tommy had hallucinated it into some menacing creature made of slabs of liver. With a history like that I just couldn't bear to see it thrown away. It's doing quite well in the bathroom.

People with HIV/AIDS also wrote about how concern over health care issues and treatments

in particular tend to become part of a daily routine:

> It feels good to finally be home. I just finished my last errand of the day: a covert meeting with this charming young man to whom I sell my AZT. ... I walk into my living room and am greeted by my three cats, Toxo, Clara, and lil' Cyto (that's short for Toxoplasmosis, Clarithromycin, and Cytomegalovirus). Every couple of weeks I change their names to a treatment, a side effect, or my latest diagnosis. They're staring at me with that guilty little we-threw-up-something-on-the-answering-machine look on their faces. Rather than check, I slump down onto the couch and grab the remote.

The representation of people living with HIV/AIDS as ordinary also includes their work, interests and passions. [7] In terms of interests, those profiled often mention involvement in sport and exercise as part of their daily routine. For instance, as written in *POZ*,

> Enos sees a parallel between athletic training and living with HIV. 'It's like being a marathon runner. You just pace yourself. You slow down and stretch emotionally. I take my mind off AIDS. Take time off from working for an AIDS organization or pushing drug companies for free drugs then I do something really fun that demands my concentration and physical energy. And I feel wonderful, like this is a body I want to live in, and live in for a long time.'

Artists, athletes, professionals, models, porn stars, the unemployed, the homeless, politicians, activists, bureaucrats, researchers: all, and more, have been profiled as people with HIV/AIDS in *POZ*.

Twinned with the ordinary are representations of people with HIV/AIDS as extraordinary or exceptional. People are portrayed as exceptional based on their personal achievements and the intensity or urgency or anger that they bring to living with HIV/AIDS - particularly in the fight against AIDS. For instance, in *DPN* and *POZ* Larry Kramer is regularly applauded for this work as a writer and activist: "quite simply the most tireless activist we know. His views may be controversial, but his honestly and dedication are beyond dispute. We are all in his debt." Similarly, *POZ* recently compiled a series of profiles that it called the dream team of AIDS activists from around the world:

> A cybergeek from London. A chain smoking mom in Paris. A Colombian artist with a taste for toilets. These and 10 other unique men and women from around the world made the final cut for *POZ*'s first annual Dream Team. It's our chance to single out some of the unsung heroes whose gift for life and whose hard work down the years have proved more than a match for this cruel disease. Dream Teamers, you're our inspiration. Take a bow.

Not all of the people portrayed as extraordinary are as high profile as this Dream Team. In *DPN*, anyone living with HIV/AIDS who has openly and unapologetically, and for the most part safely, embraced their sexuality is considered to be a hero. Readers who fit this description are profiled (or, according to the editors, shamelessly objectified) naked as the zine's 'centerfold boy'. Also, in each issue of *DPN* there is a comic strip about the adventures of a "fairly happy, healthy, urban homosexual man living with HIV" who becomes 'Captain Condom' - a gay superhero dedicated to the fight against HIV/AIDS.

Generally, representations of the ordinary and extraordinary in *POZ* and *DPN* are meant to assert that people with HIV/AIDS have lives; being HIV positive may bring significant change but it does not end people's day to day lives. Profiles and stories refute the idea that people with HIV/AIDS cannot have "ordinary" lives because of sickness or ill health, nor are they are abnormal or exotic. Furthermore, not only do people with HIV/AIDS have lives, they excel at living - at a personal level and a collective level.

Disclosure

Disclosure is a third theme about living with HIV/AIDS that is prominent in *DPN* and *POZ*. Reflections by people with HIV/AIDS on revealing their health status explore a wide range of issues: who, when and how to tell; the fear of being rejected; the possibility of discrimination; the experience of being closeted; the trials of self disclosure; and the ethics of telling lovers and sexual partners. A piece in *DPN* entitled, "The Second Coming Out" for instance begins,

> I was at a friend's house the other day, and decided it was time. 'I have something
> to tell you. (Pause) I am HIV positive.' 'I know.' I took this as another piece of
> evidence that when people say they aren't going to tell anyone about my status, *they
> don't really mean it*.

Based on such accounts, it is evident that disclosure can be a complex and often difficult task.

However, in their writing people with HIV/AIDS also convey the view that being open about

their status, at some level, is integral to the idea of living with HIV/AIDS.

On a personal level, despite the risks, for many people coming out was seen as a way of

acknowledging and embracing HIV as a part of their self definition.

> In the fall of 1991, immediately following the death of actor Brad Davis from AIDS,
> Michael Kearns announced his HIV status on *Entertainment Tonight*, becoming the
> first openly HIV positive actor in Hollywood. 'What is in your head?' asked one
> friend after Kearns' decision to nationally come out with his HIV status. Asked the
> same question today, Kearns responds, 'Self love, self worth, and self respect. If
> another actor had to die in a state of closeted shame, nothing had changed in six
> years since Hudson's death. (*POZ*)

In some accounts, the experience of coming out as HIV positive and gay was seen as being

intertwined - particularly when disclosing to family and friends.

> Telling my family was hard particularly because they didn't know I was gay. There
> was a lot of fear, a lot of ignorance at the beginning, but I've been educating them.
> Getting them beyond the conception that HIV is a death sentence, to understand that
> HIV is something you live with has proven to be the hardest part. (*POZ*)

In a related vein, not disclosing was also described as very difficult. It was described as

causing anxiety and seemed like a form of self denial. For instance, one woman described the

difficulties of not being open about her health status at work: "I went to work the next day

and tried to be normal. I was such as actress. The only place I could really show my feelings

was in the shower: that is where I could cry." As was the case of this woman, for many

people, being open about their status was self affirming and transformative: "The toughest

part of telling the world was telling my daughter. Now ... I am ready to make my mark. I want

to talk to people, to give."

Stories and profiles also discussed disclosure as a right and as a skill. The general view

conveyed in *POZ* and *DPN* was that those living with HIV/AIDS needed to be able to decide

what is best for them in regards to revealing their health status:

> Since the late 1980s, when states passed HIV confidentiality laws and courts ruled
> that information about a person's serostatus is covered by the constitutional right of
> privacy, activists have argued that people with HIV have a right to control who
> knows and who doesn't know, in bed and at the water cooler. (*DPN*)

People wrote about the way they handled disclosure in different situations - "With sex, I tell

a guy up-front. *Boom!* If he can deal with that, then he can deal with me" - and in general. For

instance, this was the approach taken by one high profile person with HIV/AIDS writing in

POZ:

> I worked out - by instinct really - a plan to gradually inform more people. ... I first
> told my brother who was also gay and HIV positive. [After that], I knew there was
> a certain time when I had to tell my parents, for example. There was time when I
> should talk to the gay press, and there was a time I should to talk to the larger world
> about it, to the degree that I was able. All those things happened in a sequence that
> was in the end very satisfying.

For most people with HIV/AIDS who wrote for *POZ* and *DPN* the way they approached

disclosure, personally and publicly, included talking to groups about their experiences as a

person living with HIV/AIDS.

> What women are saying is that if you're willing to disclose your status, you can
> make a difference. Marian Banzhaf tells the story of one HIV positive African
> American woman that she encouraged to work for the New Jersey Women's AIDS
> Network's (NJWAN) Project Act. It was the woman's first contact with other
> women who were positive. Afterward she told Banzhaf the greatest benefit of that
> contact was that 'I lost that why me shit'. The best way to address the shame factor
> is for more women to step forward and reach out to one another.

As in this case, talking publicly was often connected to AIDS education and support programs arranged through local AIDS or PWA organizations.

It is evident that the message conveyed in *POZ* and *DPN* is that, if a person wants to live with HIV/AIDS, it is best if they are open about their health status. *POZ* even makes reference to a scientific study that provided evidence suggesting that gay men who were open about their sexuality and their health lived longer than those who were closeted. However, it is equally important that people with HIV/AIDS be careful about to whom, when, and how they disclose their health status. Stories and accounts of discrimination are plentiful. Disclosure is also portrayed as being a politically beneficial act for all people living with HIV/AIDS. *DPN* shuns those who, because of their conservative beliefs about HIV/AIDS, chose to remain closeted. For instance, in the article "Pariah Chase!" the editors give tips on how to "hunt serocloseted Republicans."

> Don't bother looking for the dead giveaway: spots. The serocloseted live in mortal fear of this condition, and are loathe to leave the house when it presents itself. By the time they reach this point, they have either killed themselves or are spending an eternal holiday at L'Institute du Prairie. Happy hunting, and remember, there are no bag limits.

In other words, by challenging the fear of disclosure and going public about their health status, those infected are, hopefully, contributing to a safer and more supportive social climate for those infected and affected by HIV/AIDS.

Stories, accounts, and profiles in *DPN* and *POZ* that examine the themes that I have identified (disclosing, being ordinary yet extraordinary, and learning of an HIV or AIDS diagnosis) challenge the dominant view of HIV/AIDS. The official discourses of health care, the state, and the mass media have, until very recently, regarded the lives of those HIV

infected with a combination of denial and suspicion. By adhering to an understanding of the disease as highly infectious and terminal, representations of people with HIV/AIDS have been preoccupied with death, sickness, and contagion. Such portrayals have provided little hope, guidance or inspiration for those infected and affected by HIV/AIDS. Instead, institutionalized discourses have served, whether intentionally or not, as a cruel form of social control. They have created and sustained the view that those infected with HIV are potentially dangerous and rather than trying to live are instead waiting or preparing for death.

The stories and accounts of people with HIV/AIDS are not simply oppositional. They also seek to provide an alternative vision of what it means to be HIV positive. Accounts of dealing with a diagnosis, managing day to day life, and disclosing are meant as a more accurate portrayal of HIV/AIDS because they are the expression of people with HIV/AIDS. However, such representations are not void of ideology. In the tradition of gay and feminist liberation politics, they encourage readers to openly accept and embrace HIV infection as a part of their identity - to become a person living with HIV/AIDS. Living in this sense does not necessarily mean, as those at *DPN* consistently point out, being overly pleased and optimistic about having a potentially life threatening disease.

> I've often said that AIDS has actually saved my life, propelling me to change, encouraging me to confront what's difficult, urging my fascination with things divine. There is nothing Pollyanna-ish in this ... .

It does, however, place emphasis on the importance of taking pride in who you are and rejecting the idea that HIV/AIDS is a death sentence. Thus, as a product of the PWA movement, by showing what people with HIV/AIDS have done for themselves, *POZ* and *DPN* seek to foster an alternative perspective - by representing 'living' as part of a PWA

collective identity - that will provide guidance, hope and inspiration for those infected and affected by HIV/AIDS.

Surviving

Similar to "living" a second key frame around which a PWA collective identity is constructed is the idea that those infected are surviving HIV/AIDS. [8] The meaning of survival in this context is multi-faceted. In very broad terms, it revolves around the need for people with HIV/AIDS to be in control of, and involved in, the decisions that affect their lives. This idea has been at the centre of the PWA self empowerment since its inception. For instance, Richard Berkowitz makes this point while reflecting on his involvement in formulating the founding principles for the movement in *POZ*:

> The PWA self empowerment movement, which has repudiated once and for all the idea of patient as victim, was officially born in June 1983. ... For the first time, 11 gay men with AIDS made the case to some 400 health care workers that people with AIDS were to play a leading role in all decisions affecting their lives. We drafted a declaration of interdependence that we presented at the close of the conference with the FIGHTING FOR OUR LIVES banner unfurled in our hands.

Since 1983, what it takes to survive and to fight for your life has broadened beyond radical political tactics to include everything from seeking a second opinion to challenging the moral indignation associated with HIV/AIDS. It has become a key part of what it means to be a person with HIV/AIDS from the perspective of those involved in the organized PWA movement.

This surviving motif appears again and again in *POZ* and *DPN*. It is conveyed through profiles of people with HIV/AIDS, and through the advice, both implicit and explicit, that is

provided for the benefit of those living with HIV/AIDS. Three themes emerged when looking

at the profiles and advice contained in *POZ* and *DPN*. I use these themes - being proactive,

being an expert, and not being a victim - to illustrate how people with HIV/AIDS have been

represented as survivors and as surviving.

Pro-Active

It is difficult to pin down what it means to be proactive. For instance, the editors of *DPN*,

in reviewing Micheal Callen's book *Surviving AIDS*, struggle with this question in their zine:

> So. The best way to survive AIDS is not to die. ... [Callen] presents 13
> interview/bios with people who have lived at least three years with an AIDS
> diagnosis. He found that there isn't much commonality between these folks, except
> that they are committed to life, aggressively so. Now, it is pretty easy [to have this
> "good attitude"] when you are not sick. It is kinda difficult to chin up when you're
> drowning in a sea of misery and drugs. So, when I say "good attitude" I don't mean
> hug your teddy, Louise Puke-Puke Hay stuff. I mean like I said before, an aggressive
> commitment to life.

Part of what is being said in this editorial is that being proactive - having an aggressive

commitment to life - is a key element to surviving AIDS; but, given that, each person needs

to pursue their own version of what it means to have a "good attitude" toward living with

HIV/AIDS.

A good example of this general approach to being proactive is the way health and health

care issues are represented in *DPN* and *POZ* - in particular the need for people with

HIV/AIDS to gain control of and access to the means to health. For instance, on a individual

basis, people with HIV/AIDS often wrote about the importance of taking steps to prevent

health problems rather than waiting for symptoms to appear: eating well; exercising regularly;

avoiding sources of stress; and placing priority on quality of life issues.

> Athletics have helped prolong my life - it works. Before I was diagnosed in 1989 I was smoking, doing cocaine, all sorts of things. But when the test came back positive, I decided to start training. And once I put exercise in my life, it replaced the bad things. I train for at least 90 minutes a day, three to five times a week. I swim 2,400 meters a week, bike 300 miles a week, run 55 miles a week, and lift weights twice a week. The harder I've worked to stay alive, the luckier I have been. That doesn't just happen by itself - living takes hard work. (POZ)

Similarly, and perhaps even more so, being in charge of health care decisions, like staying

informed regarding treatments (conventional and alternative) and having a strategy for dealing

with health care professionals, was considered by many as central to their survival:

> Diagnosed with a mere 73 T-cells, and a prognosis of a year and a half to life, ... rather than become a victim, Grinberg went to work, searching for experimental therapies. 'I do believe that those who live the longest are the people who are most resourceful and proactive with their treatment.' (DPN)

On a collective level, writing about bring proactive often acknowledges that survival is more

difficult for those people with HIV/AIDS with access to fewer resources.

> It's now absolutely clear to me that survival, even now with drugs, requires constant discipline and determination. If one gives up for a week or a month, the illness takes over. I feel that every day. That means that people who are denied opportunities to move forward will not. I'm alive in part now because I'm 47 years old, I'm a lawyer, I have a lover and a supportive family, I have good health insurance, I have access to wonderful doctors. I worry about what we do for those who are not so fortunate. (POZ)

In this spirit, stories and profiles about survival also highlight the actions of people with

HIV/AIDS who are 'proactive' on a broader scale.

> Tragically, the vast majority of people with HIV don't have money, education, or even the time to become as informed as they must be to survive. If we now let our voices fall silent, if we fail to demand and deliver access, trials and real hope for everyone with HIV, we are little more than selfish. (DPN)

This editorial calls for the continued efforts of those who are fortunate to have resources to draw on and who have been committed to creating "opportunities to move forward" for people with HIV/AIDS with fever opportunities (and helping them be more able to take advantage of such opportunities) by becoming involved in some form of activism - usually, though not exclusively, via the organized AIDS movement.

Expertise

A second theme in writing about survival is that people with HIV/AIDS are the "real" AIDS experts. Suspicion and distrust of expertise based on institutional credentials is a common feature of contemporary social movements. For instance, social institutions like the state and medicine have historically constructed gay men, women, and people of colour, as being deviant or problematic. As a result, for those who are marginalized, the 'assistance' of professionals can instead become - intentionally or otherwise - a form of social control and oppression. Similarly, the initial lack of an institutional response to HIV/AIDS, followed by reactive punitive measures, has also served as a catalyst for people with HIV/AIDS to individually and collectively cultivate their own expertise as a means of survival. In fact, the PWA movement has been based, in part, on the idea that professional forms of expertise - whether exercised by social institutions or AIDS organizations - are valuable but simply do not adequately address the needs and interests of those HIV infected and affected.

In *POZ* and *DPN*, generally, the expertise of people with HIV/AIDS is shown to be based on the lived experience of being HIV positive. This distinct perspective is often raised in reference to differences between those who are HIV positive and negative. For instance,

according to one person with HIV/AIDS writing for *DPN*, "all of my friends who are positive agree with me on this: people who are negative don't know what it is like." Or, as expressed in this account in *POZ*:

> To the negatives fighting along side us I say don't pretend to understand what it is like, just stand up and act like your lives are on the line. To the positives my message is simple: Forgive them their ignorance, for they cannot understand. Then make sure they do.

In terms of expertise, it is by "knowing what it is like" that people with HIV/AIDS have acquired a knowledge of HIV/AIDS that is considered to be essential to their survival. In this sense, people with HIV/AIDS can lay claim to an authentic voice on issues regarding HIV/AIDS.

This expertise is expressed, on a personal level, by people with HIV/AIDS as a belief in their own judgement when making decisions that affect their lives. A recent example of this is writing by people with HIV/AIDS who are struggling with the decision to take a new type of medication called protease inhibitors. In the following case, the decision was made to re-evaluate the use of this medication, despite pressure from a physician, because of side effects:

> Finally I took back control of my life and my medical decisions. I stopped taking ritonavir and felt better in three days. I have gone on some new drugs, at my own pace, slowly and carefully. I have made my happiness and taking care of myself a top priority. I have committed to as few medical treatments as possible. Making your own medical choices means becoming educated about the disease and the treatment options available to you. That means a lot of hard work and becoming your own doctor. I've made my own choices and I've lived with the consequences. But at least I'm still alive. A lot of people who blindly put their faith in the hands of a doctor aren't.

In addition to people with HIV/AIDS taking care of themselves, expertise is also represented on a broader scale in *POZ* and *DPN*. Articles, for instance, often make the case that the

chances of survival are greater if those infected were able to influence decisions, made at a organizational and institutional level, that affect their lives.

> As the meeting with the drug company dragged on, I thought I had the answer. We who had the disease were discussed like hunks of meat destined for different hooks. ... As PWAs we often expect other people to take care of our battles, but some wars can only be fought by ourselves. We all love - and need - to be taken care of. When we give up control of the institutions that are supposed to be serving our needs, however, the process loses touch with reality and no one is served. As I so tartly pointed out, the failure of the company's drug wouldn't mean a falling stock price for me or loss of face in the activist community. Failure would mean death. (*POZ*)

As this person explains, despite the best intentions, the general view expressed in *POZ* and *DPN* is that in order to survive people with HIV/AIDS need to draw on their lived experience and use this knowledge to "speak and fight for themselves."

Not Victims

The remaining theme about surviving is that people living with HIV/AIDS are not victims. In terms of the PWA movement the victim label has negative connotations for two reasons. First, early in the epidemic PWA activists declared that they, "condemn attempts to label us *victims*, a term that implies passivity, helplessness and dependency on the care of others. We are people with AIDS." Later in the epidemic, as HIV spread, victim began to be used as a way of distinguishing between those who were innocent (hemophiliacs, women, children) and those who were deemed guilty (gay men, injection drugs users, people of colour). According to proponents of this view, the former were excused and pitied whereas the latter were scorned and punished. As a result, many people with HIV/AIDS rejected the victim label yet again and condemned the division between the innocent and guilty as a form of moral

oppression: "people look at me as an innocent victim who wasn't doing anything wrong, who doesn't deserve this. Well, that's just frustrating, no one deserves HIV/AIDS." Proponents of this oppositional view make the point that how people are infected is not relevant to their survival.

In *POZ* and *DPN*, the victim label is contested in several different ways. First, in profiles and personal accounts, those who are considered to be "professional AIDS victims" are shunned, exposed, and silenced. In fact, the editors of *DPN* regularly present awards to people with HIV/AIDS who they consider reprehensible. For instance, the Golden Pariah is given to people with HIV who the editors feel have been traitorous to the community - like a truck driver in the United States who was, apparently, infected from gaybashing. The editors of *DPN* have a second award for AIDS victims called the Silver Sniveller:

> the Silver Sniveller goes to our nation's favorite innocent victim, Kimberly Bergalis. As you no doubt know, Kimberly got the icky virus from her dentist. We can understand her being upset, but standing up on her rickety legs in front of the Senate panel and whining, 'I didn't do anything wrong! I'm innocent!' was inexcusable. Even more inexcusable was the way the media, especially Time Magazine, fawned over her, perpetuating the 'guilty victim vs. innocent victim' fallacy through another ratings sweep week.

This explicit shunning of those who are perceived as AIDS victims is not a prominent feature of *DPN* or *POZ*. Instead, a more common critique of the victim label is provided through testimonials from those who have felt morally oppressed as a result of their health status. For instance, as one elderly women with HIV/AIDS wrote, "people thought I was a dirty old slut because I got HIV through sex. I would have been OK if it was a blood transfusion." Similarly, testimonials from people who have overcome accusations of guilt or immorality are

also common, as in the case of this profile of an HIV positive gay men with a religious

background:

> Coming out to his father was met with outrage and admonishments, tempered by
> love. His dad reverted to his fundamentalist roots and wrote to his son, expressing
> sadness that Bryan's life had been 'devastated by making such bad choices.' Byron
> replied, 'It's a viral issue, not a moral issue. I am not being punished by God.' (*POZ*)

In many cases, involvement in AIDS organizing is often cited as an important factor in

bringing about this 'liberation' or shift in thinking about the disease.

> Consider Jane Fowler: 'I didn't want to answer the question, 'What are you doing?'
> with the statement 'Waiting to die from AIDS.' she says. 'But alone, I could almost
> forget that I perceived myself as tainted and 'dirty' because of my infected blood.'
> Then, four years ago, Fowler decided to 'liberate' herself - and try to help others -
> by becoming a public PWA and, eventually, an activist. She began by signing up as
> a speaker for Good Samaritan Project, Kansas City's oldest and largest AIDS service
> organization. (*POZ*)

In the same spirit, AIDS organizations are criticized for excluding people with HIV/AIDS,

particularly early in the epidemic, based on, as expressed in this editorial, "the all-too-

prevalent view, even then, that 'AIDS victims' had no business directing - or helping to direct

- a professional organization."

Overall, the material in *DPN* and *POZ* on the victim label focuses more on the 'innocent

vs guilty' fallacy than the passivity and helplessness associated with the label, though they are

often intertwined. For instance, as the editors of *DPN* are found of saying, "that is right

kiddies, we don't care how you got HIV, as long as you are not a whining and hateful virgin

about it." Regardless of the focus, often the central point of this writing is that self identifying

as a victim, or similarly feeling guilty or immoral about HIV infection, serves as a barrier to

survival. On an individual basis, it prevents people from being actively involved in decisions

that affect their health and health care. Collectively, it creates divisiveness among people with HIV/AIDS when they should be working together in the fight against HIV/AIDS. For these reasons, people with HIV/AIDS are encouraged, as best they can, to reject the victim label and the baggage associated with it. In the words of Sean Strubb, the founder of *POZ*, "our magazine combats the notion of victimhood on every page."

The themes about surviving HIV/AIDS - being proactive, being an AIDS expert, and not being a victim - are in many respects about resisting institutional colonization through self empowerment. In profiles, stories, and advice columns *POZ* and *DPN* show that many people with HIV/AIDS are learning to do what it takes to become involved in the decisions that help determine whether or not they will survive. In terms of constructing a PWA collective identity, the message is not to be a victim (innocent or guilty), to foster an expertise in HIV/AIDS, and to adopt a proactive stance toward living with HIV/AIDS. By adopting this understanding of the self, it is thought that people with HIV/AIDS will be, and are, better able and equipped to take control of the decisions that affect their health and their lives. In adopting various survival strategies there is a common sense of urgency and anger regarding the way in which public institutions have responded to the epidemic. Survival through self determination is seen as necessary given that social institutions consistently fail to address the needs of people with HIV/AIDS and continue to oppress those most affected by the epidemic.

Belonging

The remaining frame of reference in the construction of a PWA collective identity is the sense of belonging to a supportive and diverse community of people infected and affected by

HIV/AIDS. This idea of community membership is expressed in the creed "You Are Not Alone" written by Michael Slocum and Jim Lewis. It was first published in *Body Positive*, but has been reprinted in nearly 300 HIV/AIDS publications around the world:

> It possible to have a positive attitude as a person living with HIV - millions are doing it right now - but it is much more difficult to get on with your life and live happily if you're trying to do it alone. There's no need for you to handle this by yourself, and it's probably a mistake even to try to do it. You are not the only person facing this. Learn who the others are and what they have to offer. Just hearing how someone else has adjusted to living with the virus can be enough to help you realize that life is still good, that you can still have love and laughter. And you may also be surprised to learn that your own sharing can help others. In sharing the issues that concern us, each of our voices lends strength to the others.

Self empowerment has always been central to the PWA movement. But, as the above excerpt suggests, priority has also been placed on developing and creating a community, or communities, of people living with HIV/AIDS. Indeed, fostering an sense of belonging, as a means of fostering mutual support and education, has been represented as a key component of self empowerment within the PWA movement.

Many of the profiles, stories, and advice columns in *DPN* and *POZ* make reference to an HIV/AIDS community. In fact, the term is used quite broadly and loosely. Representations are predominately of an organized HIV/AIDS community: those infected and affected by HIV/AIDS who are involved in, or connected to, the AIDS movement (AIDS service organizations, political advocacy groups, PWA coalitions, and so on). Beyond that, though, references are made to a more general, silent and abstract HIV/AIDS community, presumably referring to all people infected and affected, including those who are at the margins of, or not involved at all in, the AIDS movement. Lastly, in many cases a distinction is made between different communities infected and affected by HIV/AIDS. I have selected three themes -

solidarity, diversity, and division - that are predominant in *DPN* and *POZ* and portray people as belonging to and dissenting from a diverse HIV/AIDS community.

Solidarity

The first theme is solidarity among people living with HIV/AIDS. In profiles, stories and editorials, people are portrayed as having a sense of togetherness or community based on their shared experience of living with HIV/AIDS.

> I talked a lot at the Quilt, and it brought me closer to my fellow positiods. It made me feel really proud to be HIV positive. ... Before speaking up, I felt indifferent to it all - I'll take pride over that any day! My family got to meet my positiod brothers and sisters also, and that was really important. They too were overcome by pride. They realized it wasn't just us - there are so many others, and we are all connected. (*POZ*)

As in the above case about attending an event at an AIDS Quilt installment, being among those HIV infected is said to create a sense of connection because people are able to speak openly about their personal fears or the social stigma related to HIV/AIDS without fear of rejection and with the knowledge that those listening will understand what they have experienced.

Quite often, representations of solidarity are about the opportunities that people with HIV/AIDS have to interact on a social basis. Predictably, much of the intermingling between people with HIV/AIDS occurs within the context of the organized AIDS movement. Indeed, being involved in self help initiatives, education programs or generally working together in the fight against AIDS is considered to be a source of solidarity among those infected. An

account of the initial formation of the PWA movement, quoted in part previously, provides

a good example:

> We came to Denver as sick people and left as activists. The friendship and romances
> forged kept us alive and fighting for years to come and, of course, made the deaths
> terrible to bear. We marched in parades, testified before legislatures, started
> newsletters and hot lines, organized PWA coalitions. ..We gave the most stigmatized
> disease of our time a human face. (*POZ*)

Portrayals of solidarity arising from interaction or mutual participation are not limited to

AIDS organizing. For instance, personal accounts frequently describe experiences in HIV

positive only, or HIV positive dominated, social and cultural arenas. In this excerpt, a gay

man with HIV/AIDS makes the case that HIVers are sexier:

> The Cruising Bar is almost completely an HIVer domain. Sure, there are a few vestal
> virgins roaming the back rooms and dark corners. But they are all HIVer wannabes
> anyway. It's those of us with the Bite who are out until 4:00 AM three or four times
> a week. It's not that I don't like non-HIVers. I'm just tired of them spending so
> much of their time and energy trying to 'protect' and 'prolong' their lives rather than
> living the one that they've got. (*DPN*)

The underlying notion in many accounts is that, given the opportunity, a sense of solidarity

will emerge when people with HIV/AIDS get together, for whatever reason.

Representations of solidarity also have a tendency to emphasize the benefits of meeting

with HIV positive friends, going to bars or socials for those infected, or attending a political

demonstration. As expressed this except from *DPN*, contact with fellow HIVers is said to be

an important form of social support.

> When your friends are dying one by one and/or your own health is a wild roller
> coaster ride, doom-and-gloom may pervade your world. If these feelings persist,
> don't suffer in silence. ... And don't forget one oft-ignored approach that's lifted the
> spirits of thousands: Community self empowerment via PWA advocacy groups,
> buyers clubs, and ACT UP. The AIDS activists movement, which has one so many

victories for PWAs, remains one of the best depression fighters - and lifesavers. Join the fight!

And on a more pragmatic level, sharing personal experiences is a valuable way to learn more about how to live with HIV/AIDS. A good example of this is accounts from conferences, workshops and retreats attended by people with HIV/AIDS. People often remark how such trips are valuable in terms of becoming more informed by meeting and talking with others who are infected. On this level, solidarity is about developing and sharing practical forms of knowledge about how to manage HIV infection.

In general, then, a sense of solidarity is portrayed as being integral to people with HIV/AIDS having a sense of belonging to a broader community. Interestingly, the social interaction that is said to promote this sense of togetherness is actively encouraged. For instance, like many publications by and for people with HIV/AIDS, *DPN* has a personal column at the back of each issue: "We at *DPN*, ever eager to help our adoring fans meet one another so that they may better sing our praises, offer the exclusive '*DPN* Meat Market.' The guidelines are simply: you can say anything legal you want except straight acting." *POZ* does not have a personal column. Instead, the magazine often has advertisements, like this one, from companies that offer HIV positive only social events and leisure activities: "Alyson Adventures: Join other HIV positive single men for a week in Arizona. .. We have planned a jeep tour, hiking, and lots of free time to relax by the creek or head off with new friends and explore the region's many attractions." Judging from such material, it is evident that *POZ* and *DPN* mean not only to represent solidarity, but are themselves part of efforts within the PWA movement to create and promote a sense of solidarity among those who are infected and

affected by HIV/AIDS. In this respect *POZ* promotes solidarity among those who are fortunate enough to have the resources and the interest in the kinds of consumer-oriented lifestyle projects and adventures that are advertised in the magazine.

Diversity

In addition to solidarity, a second theme about belonging is the diversity of people living with HIV/AIDS. Writing in *DPN* and *POZ* often makes reference to the fact that HIV/AIDS affects people with widely diverging backgrounds. For the most part, though, the general view is that this diversity can be a source of strength, not discord, among people with HIV/AIDS. In fact editorials, for instance, rally behind acknowledging diversity as a means of working toward addressing the needs and concerns of all those infected and affected by HIV/AIDS. Diversity is a prominent theme in *DPN* and *POZ*, in part, because for so many years HIV/AIDS has been associated with predominately white, professional or middle class, gay men. This belief has been reinforced by images and stories in the mainstream media. However, as this person suggests in *DPN*, it a belief also held by those HIV infected and affected: "I confess. I am one of those HIV queens who thinks - yes, now get ready to press your ME TOO buttons and be properly ashamed of yourself - HIV is essentially just a fag problem."

Representations of diversity tend to be a response - implicit and explicit - to the idea that people with HIV/AIDS are primarily gay white men. On one level, portrayals are careful not to diminish the extent to which gay men are, and have been, affected by HIV/AIDS. Like much of the organizing that has emerged from the AIDS movement, *POZ* and *DPN* were

founded by gay men and are sustained and inspired by members of gay communities across

North America. In this context, profiles, stories, and articles in *POZ* and *DPN* often stress that

the gay HIV positive community is diverse. For instance, in this essay from *POZ* the point is

that not all gay men with HIV/AIDS have the resources to take control of their lives:

> I'm a gay, white male with a personal physician who has a large AIDS practice. I am
> still alive and relatively well. But what about those who aren't gay, white men with
> personal physicians? Where does that leave the majority of people with HIV who
> aren't self-empowered? And just because someone's a gay, white male doesn't
> guarantee they'll join the self empowerment movement. For every self-empowered
> queen like myself ... there are many more gay men who choose the easier path of
> denial until it's too late.

The general message conveyed in *DPN* and *POZ* is that HIV/AIDS continues to affect gay

men. The message is also that HIV infection is not simply an issue for those who have been

stereotypically linked to the disease; it infects and affects gay youth, elderly gay men, bisexual

men, gay men of colour, men who have sex with men but don't identify as gay (straight

acting, in *DPN* terms), gay men who are HIV negative, gay injection drug users, and so on.

This writing often emphasizes the need for the gay HIV positive community, and the gay

community in general to be united in a continued response to the AIDS epidemic.

Representations of diversity do not, by any means, focus entirely on gay men. *POZ* and

DPN have tried to provide a broad portrait of those who are living with HIV/AIDS. In the

words of the editors at *DPN*, "we've been fairly boy oriented so far, but we love girly pariahs

too, yes we do. Don't be shy? Let us know you're out there." Despite such efforts, during the

relatively short life span of *DPN*, the writing remained primarily "boy oriented" though not

exclusively gay; several of the *DPN* centerfolds, for instance, were of heterosexual IV

injection drug users. *POZ*, though, has been more intent on being a forum for a diverse range

of people with HIV/AIDS. The profiles section of the magazine have made a conscious attempt at heterogeneity. Gay men, lesbians, heterosexual men and women, transgendered, bisexuals, people of colour, hemophiliacs, injection drug users, transgendered, professionals, the unemployed, the homeless, artists, activists, the educated and uneducated, the religious and the nonbelieving: this is just a partial list of the range of people who have been profiled in two publications. In a related vein, diversity in *POZ* is also represented in feature articles on communities of people with HIV/AIDS whose needs and concerns have been neglected. The following is a partial list of the topics about people with HIV/AIDS that have been addressed in *POZ* since its inception: Youth and HIV, women and HIV, the deaf and HIV, prisoners and HIV, models and HIV, porn stars and HIV, hemophiliacs and HIV, children and HIV, sex trade workers and HIV, politicians and HIV, and race and HIV.

In terms of belonging, this writing about diversity attempts to portray an HIV/AIDS community that includes all of those groups and individuals who are HIV infected and affected. In doing so, *POZ* and *DPN* attempt to show that HIV/AIDS is not limited to a single group or community and that there is no single type of person living with HIV/AIDS. Of course there are limits to such representations. For instance, in *POZ* and *DPN* there is a tendency for both publications to focus on those who are in some way connected to AIDS organizing. However, within these limits, the point of representing the disease in this way is to create bridges between the diverse groups that are infected and affected by HIV/AIDS. In many respects, the image of diversity is that of a community of communities: gay men; women; injection drug users; people from different ethnocultural backgrounds. Increasingly,

there is a sense that each community of people with HIV/AIDS, because of their differences, is working separately toward the same set objectives regarding the fight against HIV/AIDS.

Division

The remaining theme about belonging is the divisions that exist among people living with HIV/AIDS. It is evident that *POZ* and *DPN* are committed to the idea that HIV infection is enough to sustain a community of people from diverse backgrounds. Nonetheless, it would be naive to represent relations between those infected as being purely harmonious. Instead, by portraying divisions *POZ* and *DPN* acknowledge the conflict and dissent that exists within the organized HIV/AIDS community.

One way that this division or discord is represented is through material that focuses on how the needs and interests of certain people with HIV/AIDS have been neglected. For the most part, this appears as intended special features about the needs of specific groups of people with HIV/AIDS. A special issue of *POZ* on women in 1995, for instance, was spurred at least in part by the fact that the health needs of women with HIV/AIDS have been largely ignored.

> Several hundred pissed-off women on the steps of the Food and Drug Administration (FDA) last September passed a microphone around to point out that though women are the fastest growing group of people with AIDS, the FDA still restricts women's access to treatments and won't do more than 'suggest' that women be included in drug trials. So why weren't several thousand women grabbing at that mike? Why the hell aren't HIV positive women rioting?

Articles like this one, on organizing among women with HIV/AIDS, include accounts of how difficult it has been working in a social movement that has been dominated by gay men:

The Gay Men's Health Crisis has adapted its support structure for prevention and treatment to meet the needs of women living with HIV/AIDS. Five years ago, women thought GMHC stood for Gay Men's Health Club. While there are now more services, there's still resistance to taking women and AIDS seriously. Some are still very threatened by the issue of self-empowerment.

A second way in which divisions are represented is through profiles or testimonials of people who have overcome feelings of dissent or anger over the course of their life with HIV/AIDS. Such accounts are predominately by women with children and hemophiliacs. Similar to representations of victimhood, many are angry because they were infected through heterosexual intercourse or, in the case of this man, through the blood system:

Having no grasp on the politics of AIDS, Terry leapt to the conclusion that his infection was all the fault of gay men who had the virus and had donated blood. 'When I tested positive I wanted to kill all the faggots I saw,' he says, 'then I got educated.' With mounting political discontent, Terry quit the National Hemophilia Foundation and turn to ACT UP, a treatment activist group made up of mainly gay men who shared his sense of urgency. But Terry never left behind his hemophilia community; he sees his work as primarily about building bridges. (*POZ*)

In each case, whether accounts of activism or stories of personal transformation, the division among people with HIV/AIDS is articulated, but in a controlled way, one that emphasizes how the situation is improving.

In contrast, letters to the publication, though still edited, still provide more opportunity for unmediated dissent. In terms of input from readers, letters are one way of portraying anger in a constructive way. For instance, recently *POZ* profiled a HIV positive woman as a *POZ* centerfold (perhaps taking the idea from *DPN*) because she was a former playboy playmate. This feature sparked months of discord from readers. One gay man wrote,

As a gay man, I'm very disappointed and, frankly disgusted with your June 1998 issue. Who wants to see a straight woman showing her tits practically exposed on the front cover? I don't and I'm sure most of your gay male readers will want to

puke. What a turnoff! This story doesn't belong in *POZ*. I think I will burn it. Shame on you! (*POZ*)

With a similar sense of anger as this reader, a woman with HIV/AID also responded to the same article through a letter to the editor,

> I couldn't help but feel insulted and angered at the cover portrayal of Rebekka Armstrong. I am shocked that women continue to be objectified and treated on only a sexual level. Will women ever be taken seriously? Without a doubt, *POZ* appears to be written by and for men. Women remain outsiders, only viewed and portrayed as men would like to see them. (*POZ*)

Examples of such tensions and division between people with HIV/AIDS are not limited to gender. There are similar divisions between people who are HIV positive and HIV negative and between people with HIV/AIDS who received tainted blood versus those who seroconverted through some other means.

Even though representations of division are about anger and discord among people with HIV/AIDS they are still about belonging. The frustrations expressed by women, hemophiliacs, and gay men, whether through stories, articles or letters, are real. In giving voice to this dissent, *POZ* and *DPN* are intentionally and delicately including those who feel this way. By showing how people have struggled to overcome such feelings, *POZ* and *DPN* are themselves also building bridges and nurturing a sense of belonging to a broader HIV/AIDS community.

The themes that I have examined - solidarity, diversity, and division - are about constructing an illusion of community. Like the "You Are Not Alone" creed writ large, *DPN* and *POZ* try to construct a PWA collective identity in which people with HIV/AIDS belong to a united though diverse community. Social institutions prefer to deal with individuals rather than groups, or collectives, or communities, particularly when the individuals in question are

angry or perceived as a public health threat. The mandatory testing debate, for instance, is about the identification of individuals for the purposes of social control. Anonymity, in contrast, allows for more openness and does not conform well to attempts at individuation. Institutions like the state, media, and health care system, then, as social forces have contributed to the isolation and individuation of people with HIV/AIDS. In response, *POZ* and *DPN* have attempted to counter this process by constructing an portrait of those infected as member, as belonging, to a broader collective of people living with HIV/AIDS.

Conclusion

I began this chapter by arguing that *DPN* and *POZ* are counter hegemonic in that they are expressions of people with HIV/AIDS who are involved in and have been informed by the PWA self empowerment movement in North America. I illustrated how the representations in both publications constructed what it means to be a person with HIV/AIDS. I referred to this media representation as a PWA collective identity. By profiling and telling the stories of people living with HIV/AIDS, the publications are providing an alternative to the dominant view of HIV/AIDS. This analysis raises several questions and issues about the PWA movement and about media projects like *DPN* and *POZ.* [9]

Initially, the PWA self empowerment movement emerged in a social climate that was hostile toward those infected and driven by a relatively homogeneous group of gay men. Perhaps one of the most difficult challenges that the PWA movement has faced is adapting to a less oppressive social climate and a more diverse range of people infected and affected by HIV/AIDS. Constructing a collective identity - a means of self definition that is about HIV

infection - is essential to this process of adaptation. More than ever the viability of 'living with HIV/AIDS' as an identity is being questioned. It is evident in recent issues of *POZ*, especially, that many people with HIV/AIDS no longer feel a strong sense of urgency and fear, in part, because of the recent developments in treating HIV/AIDS. In response, there is a hint of a resurgence in the fight against AIDS. For instance, *POZ* now carries the subheading, "Because AIDS Isn't Over." A greater focus is being devoted to the AIDS crisis internationally and to the great number of people with HIV/AIDS that have limited access to personal and collective resources. There is constant debate about the benefits of and problems with the use of protease inhibitors. As HIV/AIDS does become recognized as more chronic and manageable, it will be interesting to see the fate of the PWA self empowerment movement - whether or not people with HIV/AIDS will continue to rally around issues related to the epidemic or hand this concern over to social institutions.

Of course, the future of the PWA movement raises serious questions for media projects like *POZ* and *DPN*. Recently, a journalist writing for *POZ* profiled *DPN* when it ceased to exist. The argument made was that the age of politically informed AIDS projects was over; there was a need in the late 1980s and early 1990s, but currently, radical AIDS activism had been completely institutionalized. It does seem apparent that fewer *DPN* - like projects are arising from the PWA movement and that there is a trend toward more professional all inclusive magazines like *POZ*. In fact, more and more *POZ* seems to be moving toward a model in which an HIV positive intellectual elite write and publish helpful and inspirational material for the remaining HIV positive community. However, as a PWA collective identity becomes increasingly fragmented, and perhaps muted, there maybe a rise in media projects

about AIDS that are not necessarily exclusively AIDS focused. Projects by and for addicts

with HIV/AIDS, for instance, may focus more on addiction than HIV infection. In addition,

it may also be a case that many people with HIV/AIDS are using the internet or other media

more than desk top publishing voice their concerns. *POZ* has featured several web pages

published by individuals with HIV/AIDS which are informed by the ideology of the PWA self

empowerment movement. It may be the case, then, that media projects by and for people with

HIV/AIDS may not be disappearing but re-appearing in different places.

FOOTNOTES

1. It is interesting that more research has not been devoted to changes in the representation of people with HIV/AIDS given the number of studies conducted in the late 1980s. Examining the more subtle forms of dominance - attempts to contain and control the meaning of HIV/AIDS - as evident in 'progressive' representations of HIV/AIDS in the mass media would be a interesting topic for future research.

2. In fact, the magazine has extended itself to include a broader set of for-profit (or at least linked to for-profit) HIV related education and support services. In recent years, for instance, *POZ* has offered a traveling Exposition, described by critics as simply an HIV/AIDS trade show. This POZ EXPO features workshops and educational seminars but has been criticized as mostly an opportunity for companies, business, and organizations to display and advertise their products and services.

3. The emergence and popularity of *POZ* might also indicate a shift in AIDS organizing toward the private rather than public sector. Earlier forms of AIDS activism focused on the state not addressing the needs of all citizens, not just those in the mainstream. As the AIDS industry has risen in the 1990s, there has been a greater temptation to receive support from the private sector. It is still to be seen what impact this will have on community-based organization. However, in the most recent issue of *POZ* the headlines read "Save the AIDS Service Organizations" implying that many organizations are finding it increasingly difficult to sustain themselves given the lack of public and private funding.

4. This idea of a collective identity was first introduced in early collective behavior studies to describe solidarity among members of disruptive or deviant groups (Blumer, 1955). Recently, with the rise of new social movements, scholars have returned to the question of collective identity, not in the pejorative sense used in previous years, but in an attempt to examine the cultural aspects of collective action (Morris & Mueller, 1992).

5. Ironically, many of the early portrayals of people with AIDS were in fact of men with syphilis. Nonetheless, this image became twinned with HIV/AIDS and continues to inform the public imagination about the image and fate of those infected.

6. Based on comparisons with stories published earlier on the epidemic, in publications like *Body Positive*, it would appear that testing methods and those health care professions involved in testing have improved the way they approach informing people about their infection. Earlier accounts often expressed anger at being told by physicians that they were going to die in a very short period of time. More recent stories, though not all glowing, either do not discuss in detail the role of health professionals or are more complimentary about the way they were informed.

7. Profiles and stories of this type appear most often in *POZ*, in part, because of the emphasis that is placed on lifestyle. Focusing on lifestyle makes sense given that *POZ* has been, by and large, modelled - albeit as a critique - after mainstream lifestyle magazines. Despite the diverse range of activities and endeavors, there are some social spheres that appear on a more regular basis. For instance, it is common to read about the involvement of people with HIV/AIDS in the arts, the media, sports and leisure, politics, and pornography.

8. This theme has also been quite prominent in writings by people with HIV/AIDS. It is central to Michael Callen's book, *Surviving AIDS*, which documents his life as an AIDS activist and as a person with HIV/AIDS. Similarly, in an early and influential resource guide for people with HIV/AIDS, published by PWA Coalition of New York, *Surviving and Thriving with AIDS*, survival refers to what people have achieved and what they are trying to encourage other to work toward.

9. An important issue that I have not been able to address in this study is the influence or impact of a PWA collective identity on people living with HIV/AIDS. It is unclear as to, first of all, what extent people with HIV/AIDS read and use publications like *POZ* and *DPN*. Based on letters to the editors, those infected in isolated areas, like prisons, greatly rely on publications as a source of support and education. However, beyond this it is unclear who reads *POZ* and *DPN*. Also, a PWA collective identity, as least as envisioned by theorists like Melucci, is supposed to be an emergent process among those connected to a social movement - this helps to ensure that meanings are consistent with the needs and concerns of those participating in collective action. It is unclear whether the PWA collective identity represented in *POZ* and *DPN* is a resource for people with HIV/AIDS or whether it serves to impose unrealistic expectations on people who are trying to cope with a disease the best way that they can. It would be valuable to explore such questions regarding use of media by people with HIV/AIDS in future research.

CHAPTER EIGHT: CONCLUSION

In his book *Community and Power*, Altman (1993:1) argues that the community based response to HIV/AIDS has been effective and subversive because "it has challenged the 'expert' control of knowledge and the state's control of policy." In many respects, organizing by and for people with HIV/AIDS has been at the forefront of this challenge. Using strategies of self empowerment, the PWA movement has encouraged and assisted the involvement of those infected in all decisions that affect their lives. Being involved has meant reworking and changing the societal norms and assumptions about what it means to be a person with an infectious, life threatening disease.

In this study I have focused on one aspects of this movement: media activism by people with HIV/AIDS. Activism in this case does not refer to actions directed at transforming the mass media. Instead, my approach has been to view the development of alternative print media projects as a form of activism. By developing public forums, people with HIV/AIDS have created a means of providing mutual support and education that was not otherwise available. In addition, such forums have been used as a means of influencing and challenging those power structures that control public policy decisions regarding HIV/AIDS.

In this conclusion I touch on several different themes. To begin, I situate media activism among people with HIV/AIDS in relation to social movements in health that have also emphasized self empowerment and community development. Looking at PWA media in this

broader social and political context is useful in order to understand the role of alternative public spheres in contemporary social movements. Second, I look at the contribution of this study to literature on the social aspects of HIV/AIDS. Third, I return to the theoretical focus of this research by returning to questions surrounding the function of alternative media in the construction of an alternative public sphere. Fourth, I suggest several potential areas for future research. And last, I turn to more practical concerns by outlining several implications for the use of alternative print media as a form of activism.

Social Movements in Health

Since the late 1960s, health has become a significant site of political struggle in contemporary social movements. A greater awareness of the relationship between health issues and social structural inequalities around gender, sexuality, class, race and social stigma provides a common ground between the women's health movement, the independent living movement, organizing around gay and lesbian health, the community-based response to HIV/AIDS and social movements in health in general (Bayer, 1986; Sears, 1991). As Sears (1991:42) has noted, such community organizing arose "out of the intersection of a health crisis and the struggle against oppression." In each case, activists have mobilized in response to the societal neglect shown toward the civil rights and the health and social needs of marginalized or oppressed communities (Clarke, 1993; Withorn, 1980; Leonardis & Mauri, 1992; Wilkinson, & Kitzinger, 1993).

In the context of social movements in health those most affected by health problems and social issues have been encouraged to organize in order to question and challenge the

expertise exercised by health professionals and state officials. In doing so, they have demanded that health be treated not exclusively as a physiological condition, but as a social and political issue that must be addressed. This type of political organizing around health has been referred to by Sears (1991:32) as 'health from below':

> the politics of health from below often starts with concerns about the coercive aspects of state control. [It is] a struggle through which those most affected by specific health threats take power over the resources, knowledge and conditions of life necessary to procure well-being.

The idea of 'health from below' suggests that with the threat of colonization and institutional control, women, people with disabilities, gay men and lesbians, and people with HIV/AIDS are collectively realizing the need to struggle for self determination and control of their bodies and their lives. Organizing among people with HIV/AIDS has often been seen to be at the forefront of efforts to put the principles behind 'health from below' into practice. For instance, in the case of women with breast cancer, Winnow (1992:71) has noted that,

> cancer, like AIDS, is about living. It is about living with a life-threatening disease, in whatever state, in whatever condition. We desperately needed a ... centre where women with cancer could be empowered to make their own choices and be supported by other women - a centre controlled by women with cancer. I knew this vision was possible because the models had already been built for AIDS.

As Winnow suggests, in social movements in health generally, organizational models based on self help and self empowerment have become recognized as a means of addressing the needs and concerns of those who are marginalized or oppressed and facing serious health problems.

In this study I have looked at how models of self help and self empowerment have been applied to media projects in order to create public forums by and for people with HIV/AIDS.

The chapter on newsletters, for instance, illustrated how print media, as a form of communication and representation, became integrated into the core programs and services offered by PWA organizations. Similarly, the analysis of treatment publications looked at how groups of people with HIV/AIDS organized and started their own media projects as a means of helping those infected and affected make informed decisions regarding their health care. And lastly, the chapter on general interest magazines demonstrated how those infected used print media to contest, transform, and reconstruct the meaning of HIV/AIDS, particularly in terms of challenging how living with HIV/AIDS is understood. What is evident in each of these chapters is the importance of communication - having in place forums through which people with HIV/AIDS can share their experiences and knowledge - in the struggle for self representation and as a resource for survival.

I have argued that developing such forms of communication (public forums, print media, telephone hotline, web sites) is an attempt by those involved in contemporary social movements to create an alternative public sphere. The significance of an alternative public is twofold. First, it is a social space made up of peers that is ideally independent of forms of institutional influence and control. Second, it invites not only the articulation of opposition to the dominant social order, but alternatives - different ways of understanding and being - to the status quo. For instance, people with HIV/AIDS were able to use print media to provide mutual support and education based on their lived experiences rather than professional or institutional credentials. Furthermore, print media were also used to challenge and reconstruct the dominant view of HIV/AIDS. In reconstructing the meaning of HIV/AIDS, those involved in media projects sought to provide inspiration and hope rather

than dread and fear. It is in this sense that media projects are more than simply a way of resisting hegemony; instead, they are a form of activism that seeks to create an alternative way of understanding, using and relating to the dominant social order.

This argument can be extended to contemporary social movements in health in general. For instance, studies of alternative feminist media have made the point that such forums have played an important role in raising awareness about women's health issues and in providing women with the knowledge they need to take control of their health. Limited research has been conducted on the use of alternative media by those involved in social movements in health; however, as suggested in studies of the feminist press, I suspect that media projects have played a similar role as those in the community based response to HIV/AIDS, though perhaps to a lesser extent. Media projects that have emerged from organizing among people with HIV/AIDS have benefitted from a lineage of publishing within the gay and lesbian movement. One reason why media projects may be less prevalent in other social movements in health is that they are not able to draw on this political heritage in regard to alternative media.

The development of such media projects, though often thought to be peripheral to the more pressing work of political activists, is nonetheless important - particularly in the context of collective efforts to create a broader alternative public sphere for those who are marginalized and living with health problems. Such public forums and social spaces play several important roles: they sustain and revive the political ideologies that form the foundation for social movements; they are often a practical resource for ideas and advice; and, on a symbolic or cultural level, they nurture and legitimate collective identities (ways of

knowing and feeling) that are otherwise silenced or marginalized. Zola (1991), for instance, has written about the level of self awareness and empowerment that he experienced after visiting a community in Europe that was organized and built by and for people with disabilities. After years of learning to adapt to the way cities are built in North America, experiencing such a different social environment as a person with a physical disability made Zola realize the extent to which he had internalized the dominant attitude toward those with disabilities because he had never encountered an alternative to this model.

Media projects like those in this study can be seen as part of efforts to provide those infected and affected with the opportunity and the means to understand themselves and their situation in a way that challenges, and provides an alternative to, the prevailing view of HIV/AIDS. Hence, in PWA print media, the prevailing view is that people need to understand themselves as experts more than patients, as active not passive, as members of a community rather than as isolated, as living rather than dying, and as survivors not victims. Such alternative discourse about how it is possible to understand ourselves differently, and in potentially empowering ways, is valuable for those who are trying to survive in a social climate that is not responsive to their needs or interests.

In this regard, the construction of an alternative public sphere can be seen as part of a struggle over the control of self understanding. How we understand ourselves as subjects and citizens is directly influenced by institutionalized discourse that is constructed and legitimated through power structures like government, the family, education, the media, medical science and so on. One of the key roles that social movements have played in modern industrial democracies has been to create opportunities for individuals and groups to collectively

formulate and articulate their own alternatives to the current dominant social order. The development of public forums, through media projects like those examined in this study, are an important means of moving closer towards this goal.

Literature on the Social Aspects of HIV/AIDS

In the social sciences, considerable attention has been devoted to HIV/AIDS. As Adam (1992) has noted, although researchers were generally slow to respond to the epidemic over the past ten years, the number of studies has grown exponentially. One of the strengths of this project is its contribution to the literature on the social aspects of HIV/AIDS. The areas of research that are most relevant to this project are the community-based response to HIV/AIDS, HIV/AIDS and the media, and people living with HIV/AIDS. A common theme among these areas is that each is marginal in relation to social research on HIV/AIDS in general. As a result, the value of this project is twofold. First, it advances areas of research on HIV/AIDS that deserve and need greater attention. And second, it addresses questions and issues within each of these areas that have yet to be examined.

The Community-Based Response to HIV/AIDS

Studies that examine the community-based response to HIV/AIDS have focused on aspects of AIDS organizing: the provision of support and education services, internal politics, international comparisons, its historical evolution, and its role in formulating a response to HIV/AIDS as a health crisis. For the most part, the contribution of people with HIV/AIDS to the AIDS movement has been at the background of the research on the community-based

response to HIV/AIDS. However, in recent years, more has been written on the PWA movement and on organizing among people with HIV/AIDS. There are likely several factors that have contributed to this trend. First, more than ever before, people with HIV/AIDS are taking on leadership roles in AIDS organizations. As a result, their contributions are becoming more apparent and more recognized in social research. Second, in several cases, research on PWA organizing has been conducted by people with HIV/AIDS. They have used their own experiences in the movement as a basis for conducting social research (Ariss, 1996; Roy, 1995). Although my focus is on media projects by and for people with HIV/AIDS my analysis is also indirectly and directly about the PWA movement. As a result, the publications examined in this study are a way of looking at PWA organizing and the role of those infected in the community-based response to HIV/AIDS.

One of the key points to be drawn from this study is that people with HIV/AIDS have been actively involved throughout the AIDS movement. Early on, as the newsletters in this study have shown, those HIV infected articulated a political ideology based on self empowerment and collectively formed grassroots coalitions. Even though such efforts were marginal to mainstream AIDS service organizations, they were nonetheless important in addressing the needs and concerns of people living with HIV/AIDS. Later, as the PWA movement expanded, people with HIV/AIDS became more actively involved in political activism, especially in regard to health care as illustrated by the treatment publications in this study. More recently, as suggested in all the media projects that I have examined, there is evidence to suggest that people with HIV/AIDS are becoming increasingly involved in mainstream AIDS organizing. Despite this trend, though, many in the movement still argue

that those infected continue to be underrepresented in leadership positions within organizations that claim to be community-based. To highlight the contributions of people with HIV/AIDS may seem like a simple and self evident point. However, for many years, the history of this aspect of the AIDS movement had been largely ignored. There is always also the possibility that it could again be easily written out of the discourses about the AIDS epidemic. In this regard, media projects help to remind those in and beyond the AIDS movement of the role that people with HIV/AIDS have played in the community-based response to HIV/AIDS.

In a similar vein, the publications in this study also provide a sense of how the PWA movement has evolved over the past fifteen years. Generally speaking, organizing among people with HIV/AIDS has grown from informal grassroots coalitions to formal non-profit service organizations. With this expansion, the focus and scope of the movement has also changed. Early in the epidemic, for instance, people with HIV/AIDS organized because they did not have a voice in the AIDS movement, in policy decisions, or in advancing developments in treatments. The slogan for the movement 'fighting for our lives' referred to taking control of their chances for survival by organizing and developing strategies for self empowerment. But gradually as PWA organizing developed, the input by those infected has come to be seen as a more accepted and legitimate, and even essential aspect of AIDS organizing and of the institutional response to HIV/AIDS. With this recognition, the PWA movement has become less insular in its orientation. The focus is less on the movement itself. In fact, it is uncommon to hear mention of the PWA movement except as a reference to an earlier form of activism among people with HIV/AIDS. Instead, PWA organizations are

currently more focused on providing services and programs and influencing government policies and AIDS industries. This shift in orientation has led some people with HIV/AIDS to raise concerns about the accountability of PWA organizations given the extent to which they have become formalized and externally oriented.

The media projects in this study provide a sense of the challenges that are currently facing the PWA movement. The first challenge is the threat of incorporation by power structures like the state, AIDS industries and the mass media. Earlier in the AIDS epidemic, the neglect and forms of domination that people with HIV/AIDS faced were quite explicit - moral panic, threats of quarantine, branding, mandatory testing and surveillance. Once governments started to be more responsive, largely through support to AIDS organizations, and advances were made in the treatment of HIV/AIDS, political actions among people with HIV/AIDS has become more muted. Certainly a broader societal response to the epidemic has been welcomed and is necessary. However, it changes the context of PWA organizing in way that requires strategies and approaches that can take advantage of institutional support without compromising a politics of health that focuses on the needs and interests of those living with HIV/AIDS.

A second challenge is the diversity of people infected with HIV/AIDS. Establishing a collective identity has been essential to the PWA movement. It has helped those HIV infected develop a sense of self that is not exclusively defined by the state, the media or the medical establishment. Early in the AIDS epidemic, those who called themselves 'people with HIV/AIDS' were almost exclusively gay men. The collective identity that they constructed was also a gay identity and self empowerment and gay liberation were intertwined. As a key

part the PWA movement, this collective identity has had to be revised constantly in response to the increasing diversity of people with HIV/AIDS. PWA organizations are much more diverse than when they were first established. Increasing differences in perspective have created tensions in PWA organizations, particularly as gay liberation ideologies are accepted, rejected, and transformed by those who have entered into the movement. For some, HIV infection is not enough to create a sense of solidarity between groups with such divergent social backgrounds. Advocates of the movement, though, argue that it is possible to establish a common ground between identities based on the principles of self empowerment.

Each of these challenges raises the issue of whether the PWA movement has lost its political edge. The pressure of incorporation limits the extent to which those infected can pose challenges to the power structures that control access to the means to health. Similarly, the fragmentation of people with HIV/AIDS has the effect of weakening the political foundation of the movement. Faced with this issue, advocates of the movement look in several promising directions: to an international movement of people with HIV/AIDS rallying around inequalities between developed and developing nations; to multiple forms of oppression as providing a bond between gay men, women, injection drug users, and minorities with HIV/AIDS. Clearly, a key question for the PWA movement in the coming years will be the extent to which this political focus can be revived.

HIV/AIDS and the Media

Much has been written about HIV/AIDS and the mass media. This focus on mass communication follows a general emphasis in social sciences on critical studies of the mass

media at the expense of alternative forms of communication. One of the goals of this research has been to shift the focus to alternative media projects - though not in isolation from the mass media. My approach has been to examine print media by and for people with HIV/AIDS while taking into consideration the relationship between alternative and mass media. In this regard, the contribution of this study is twofold. First, it adds to our understanding of how alternative media have been developed in the context of social movements. And second, it illustrates how people with HIV/AIDS have used alternative media to articulate their own critique of the mass media.

One of the main findings in this study is that community-based organizations have played a key role in supporting and sustaining alternative media projects by and for people living with HIV/AIDS. The necessary resources - financial, practical and ideological - were available through the organized AIDS movement. It is doubtful that there would be such publications without the presence of stable state funded PWA service organizations. It is interesting to note that this relationship between AIDS organizing and alternative media may now be changing. It is apparent that in recent years there are signs that PWA organizations are no longer willing to support small scale semi-autonomous projects by people with HIV/AIDS. In response, existing publications have begun to look for resources from other sources like funding from AIDS industries and the state. It is unclear how this will impact on media projects that were developed initially as forms of activism. Reliance on support beyond the HIV/AIDS community may place limits on the extent to which publications are able to be subversive and effective in meeting the needs and concerns of people with HIV/AIDS. As

well, the lack of support from AIDS organizations may inhibit the development of new media projects by and for people with HIV/AIDS.

Another point to be drawn from this analysis is that alternative media projects, at least in the case of HIV/AIDS, and perhaps generally, serve multiple purposes. On one level, they help to foster communication among those involved in the PWA movement. In this capacity, media projects help to formulate, legitimate and sustain political ideologies that have shaped organizing by people with HIV/AIDS. Beyond the purely political, media projects are also practical resources for people with HIV/AIDS. In addressing the needs and concerns of those infected, they rework overly complex information and provide advice that is not otherwise available. There is also a symbolic dimension to the material published in media projects by and for people with HIV/AIDS. People involved in such projects have consciously tried to challenge and reconstruct the meaning of HIV/AIDS so that it would portray those infected in a more realistic and empowered manner.

Overall, looking at these objectives, it is evident that a common thread in PWA media has been the struggle to exert control over the representation of HIV/AIDS. Arguably, in recent years, such efforts have become more difficult as institutional discourses have adopted similar strategies of representation as those initially used by those with HIV/AIDS - like the portrayal of people with HIV/AIDS in a positive and empowered way or taking into consideration their needs, interests, and perspectives in the provision of treatment information. The challenge that faces people with HIV/AIDS involved in media projects is to convince themselves, and those in positions of power, that their voice and their perspective is still essential to the way in

which HIV/AIDS is represented and that they should be involved in the process of representing HIV/AIDS to some degree.

A final point on alternative media projects by and for people with HIV/AIDS is that while print media were once dominant, it appears as if there is a shift away from print and towards electronic media. Perhaps it is incorrect to say that there is a shift away from print, because print itself is still essential to alternative media - electronic or otherwise. However, print has been reconfigured as a result of the emergence of new media technologies like the internet. For instance, in the case of HIV/AIDS, publications are still being produced but they are increasingly being twinned with electronic forms of communication which appear, at least on the surface (it is arguably too early to tell), to be more effective and legitimate. This shift may be linked to the impression that many alternative print media are ineffective in reaching people with HIV/AIDS or influencing institutional structures. They are on the fringe, marginal, alternative, and easy to ignore or miss and are often dismissed. New media technologies, it is thought, enable activists and community organizers to create media that will be recognized and noticed by the media, government and AIDS industries.

There is an interesting relationship between alternative and mass media. People with HIV/AIDS have used publications to articulate a critical response to 'official' AIDS discourses. One of the main reasons for initiating media projects was because HIV/AIDS was misrepresented by the mass media and in general. Early on, this critique focused on the irresponsible, inaccurate and even hostile portrayal of people with HIV/AIDS. The response was partially in order to give "AIDS a human face" and to portray the images and stories of those infected and affected. Indirectly or directly such struggles were effective in that the

mass media have become more sensitive to the portrayal of people with HIV/AIDS. Currently, the main critique of the mass media is much different than in earlier years. Now, organizers and activists are concerned that the situation for people with HIV/AIDS is being represented in an overly optimistic and positive way. They want to refute attempts by the media to 'announce' the end of the epidemic and the 'curing' of people with HIV/AIDS as a result of new developments in medical treatments. Increasingly, it appears as if a positive and empowered representation of people with HIV/AIDS in alternative media projects includes the difficulties and challenges that those with HIV/AIDS face as much as their victories and accomplishments.

People Living with HIV/AIDS

In the social sciences, studies about HIV/AIDS have tended to address issues of public education and prevention or the societal impact of the epidemic. As Adam (1992) has noted, there has been a lack of research on issues that are relevant to people living with HIV/AIDS. In recent years, scholars have responded to this gap by looking more at the experiences of those HIV infected. The contribution of this study to this area is in treating media projects as cultural artifacts about the experiences of people with HIV/AIDS.

Media projects like those included in my analysis have been designed, in part, to give people with HIV/AIDS a forum in which to share their experiences primarily through personal narratives and photographs. Not all of the content of PWA media is of this nature. However, many people with HIV/AIDS have taken this opportunity to express themselves, either as a means of making sense of their condition, or to help others with HIV/AIDS or both. In early

media projects there were fewer narratives and personal accounts. However, more recently publications like *POZ* and *Body Positive* have integrated the writings and stories of those infected. Writing about living with HIV/AIDS has become so prevalent that there are now several foundations supporting this work. Many people with HIV/AIDS who consider themselves writers or artists, or who have become writers or artists, have used PWA media as a forum for their material. Thus, PWA media provide an interesting look at an emergent cultural field in connection to HIV/AIDS.

This trend toward more professional writing about HIV/AIDS should not overshadow the fact that PWA media have been a forum for the experiences of a diverse range of people with HIV/AIDS. On this level, publications do provide a window on issues and questions that have been addressed regarding living with HIV/AIDS. In profiles and stories, media projects by and for people with HIV/AIDS are a testament of the difficulties that people with HIV/AIDS are facing and how they have developed strategies for overcoming or at least addressing such adversities. For instance, when the popular view of new treatments was that they were generally beneficial, the focus of many articles and stories in PWA media highlighted the devastating side effects and not the health benefits, that accompanied these medication because this was the experience of those who were actually taking the drugs. The case of new medications and the experiences of those HIV infected can be extended to numerous other issues: discrimination, sexual politics, the limitation of safe sex, and so on.

When treating PWA media as cultural artifacts it is important to consider that the experiences of people with HIV/AIDS have been represented from a specific perspective - that of the organized PWA movement. It is striking that much of the material in the media

projects in this study reflect the general ideology of self empowerment that has been so important to organizing among people with HIV/AIDS. As a result, the experiences portrayed in PWA media, though they may seem like personal accounts, are nonetheless concretely ideological. Given that all personal accounts are at some level informed by ideology, it is valuable, albeit unusual, to be able to look at the experiences of people with HIV/AIDS and know that they reflect a particular political perspective.

Alternative Media and the Public Sphere

For Habermas, in democratic societies it is important that citizens have the opportunity to put aside their differences and engage in critical debate about issues of common concern. Historically, such dialogue has occurred through participation in the public sphere. However, public spheres in most late industrial democracies are controlled by an economic and intellectual elite. As a result, the critical reason of those who are marginalized or oppressed is silenced or distorted in order to reproduce the dominant social order. A common feature of contemporary social movements is an attempt to revitalize the public sphere. From the perspective of social activists, the chance for all citizens to use their critical reason is considered to be central to redressing existing social inequities and forms of oppression. To reach this end, those involved in social movements have developed alternative public spheres so that a broader range of citizens can engage in meaningful public debate.

The role of alternative media in the construction of an alternative public sphere has been a central theoretical concern in this study. There are two aspects of alternative public spheres that are important in understanding the use of alternative media as a form of activism. The

first aspect is that alternative public spheres have both an internal and an external function. The second aspect is that alternative public spheres are forums for 'undistorted' communication. A discussion of each of these points is instructive when examining the potential role of alternative media in revitalizing the public sphere as a forum for public participation in civil society.

As Marshall (1991) has argued, theoretically, alternative public spheres have a dual purpose. By fostering and supporting the formation of collective identities, they have an internal function as part of contemporary social movements. At the same time, by providing the means by which dominant ideologies can be challenged and transformed through debate, alternative public spheres also serve an external function. In the case of the PWA movement, as indicated by the media projects in this study, the alternative public sphere that has been constructed for people with HIV/AIDS has primarily had an internal rather than external function. The focus of PWA media has not been on challenging and influencing the beliefs of those who are not infected or directly affected by HIV/AIDS. Instead, the purpose of newsletters, treatment publications and general interest magazines collectively has been primarily to give those infected a means of articulating and representing a supportive and empowered portrait of what it means to be HIV positive. This internal function of alternative public spheres is essential for the construction of collective identities in the context of social movements. However, the lack of an external focus limits the extent to which people with HIV/AIDS can work collectively to transform dominant social and power structures in North American societies.

There is evidence to suggest that media projects like those in this study have become more external in their orientation as the nature of the PWA movement has changed. *POZ*, for instance, has tried to appeal to an audience that is located beyond the HIV/AIDS community. In using the conventions of mainstream magazines, those involved in *POZ* have tried to make the publication more attractive and familiar to a broader range of people and industries. Sean Strubb, the founder of *POZ*, has said that he will consider his magazine a success when an non-AIDS specific corporation like General Motors wishes to place an advertisement in *POZ*. The extent to which *POZ* has been successful in this regard is open for debate. The publication has certainly caught the attention of those working in the magazine industry, but its readership has remained limited in scope.

The emergence and growth of *POZ* can be seen as a response to the need for the PWA movement to focus more on informing and engaging an audience other than those infected or directly affected by HIV/AIDS. In becoming broader in scope, the debate within the alternative public sphere for people with HIV/AIDS could potentially be more effective in order to challenge and transform dominant social and power structures. Most PWA media projects, however, are much more suited to performing an internal rather than external function. Alternative media in general have been criticized for only speaking to a relatively small and already converted audience. It may be possible, however, for new types of hybrid media, like *POZ*, to break down the distinction between mainstream and alternative media and influence those who would not otherwise be exposed to the perspective of those infected and affected. It is a challenge is to accomplish this objective and still remain accountable to those living with HIV/AIDS and avoid becoming co-opted by dominant political or economic

interests. In other words, in order to work toward revitalizing the public sphere, alternative media projects need to move beyond marginalized forms of communications in a way that does not result in a loss of autonomy.

A second characteristic of alternative public spheres, taken up by Downing in terms of alternative media (1984; 1988), is that they enable those who are marginalized or oppressed to communicate through forums that are free from domination. Using Habermas' phrase, the objective of the public sphere is to create a situation in which 'undistorted communication' is possible - allowing citizens to engage in debate in a manner that is not shaped or organized by dominant power structures. In the case of the PWA movement, this sentiment has been expressed by adhering to an ethic of organizing *by and for* people with HIV/AIDS. A key aspect of PWA self empowerment is that those infected need to take control of and become actively involved in the decisions that affect their lives. The potential for undistorted communication is created when people with HIV/AIDS are able to create and control forums that are designed for the exchange of knowledge and experience related to living with HIV/AIDS.

The publications in this study, to varying degrees, have tried to be by and for people with HIV/AIDS. However, it was rare for any of the media projects to actually fulfil this objective. For instance, many of those involved in *The Positive Side* and the *Treatment Information Flash* were not HIV infected. Instead, the idea of having a project that was truly by and for people with HIV/AIDS was a goal to work toward. In many cases publications developed strategies for overcoming the distinction between those infected and those not infected. The *BCPWA News*, for instance, created an editorial committee that was reserved only for those

who were infected, and allowed all non-infected volunteers to be involved in other aspects of producing the publication. Similarly, the editors of *Diseased Pariah News* began with the intention of restricting their zine to the work of those who are HIV infected but eventually chose to include contributions from those affected by HIV/AIDS. Indeed, the publications in this study in general have become more open to inviting more people who are affected by HIV/AIDS (rather than infected) to participate in the forums that initially began as only for those infected by HIV/AIDS. Even the term "living with HIV/AID" is now often used to refer to anyone who is either infected or affected by HIV/AIDS.

Contradictions that many of those involved in PWA media projects have faced in trying to create a forum that was by and for people with HIV/AIDS, when they were themselves not HIV infected, are a result of the essentialism that is a part of political struggles involving identity politics. Creating an alternative public sphere in which people with HIV/AIDS can share their knowledge and experiences in forums that are free from forms of domination is valuable. However, it is problematic if the qualifications for participation are so narrow that they exclude those who wish to contribute to such efforts or those who could benefit from debates about issues relevant to the lives of people with HIV/AIDS. Adhering to such forms of exclusion can lead those who are involved in political organizing to focus too much attention on the authenticity of particular identities rather than in building alliances between people with common political interests.

Ironically, the essentialism that provides the foundation for the construction of alternative public spheres also poses limitations on the political impact of such efforts. The fragmentation of alternative public spheres along many different and discrete identities does not provide

many opportunities for exchange between those who are involved in different contemporary social movements. And yet, it may be possible for those involved in alternative media projects to establish a dialogue between social activists who have similar or related political interests. This shift would require making explicit links between contemporary social movements. Such efforts may begin the process of bringing together a broader range of citizens who are in some way marginalized or oppressed and enable them to articulate a means of challenging and transforming forms of domination.

Directions for Future Research

In social research the issues and questions raised generally lead to directions for future projects. For instance, after completing a study it often becomes evident that there are new ways of looking at the data that has been collected. Alternatively, the more frequent scenario is that the findings of a study will point to ways in which a current project can be advanced or expanded. This study is no exception. There are several new directions for future research that follow from this project.

Looking back at this study, there is more to be said about various aspects of the material represented in media projects by and for people with HIV/AIDS. In the newsletters, for instance, it would have been interesting to focus more specifically on the issues and questions that were raised by people with HIV/AIDS throughout the course of the epidemic. The common format of newsletters, combined with their longevity, makes it possible to examine common themes (for instance, complementary therapies) and how these themes have changed over time from the perspective of those living with HIV/AIDS. It would also be interesting

to examine the content of treatment publications in more detail. On one level, treatment media projects are about providing useful information. However, at the same time, imbedded in this advice are expectations - explicit and implicit - about how people with HIV/AIDS *should* approach their health care. Looking at this aspect of treatment information would illustrate how the AIDS movement has fostered a particular form of self understanding regarding health and health care. Lastly, more attention needs to be devoted to the self portrayals of people with HIV/AIDS. For instance, much of the content in PWA media has been devoted to visual images of people with HIV/AIDS. It would be interesting to conduct a study of how such images have changed over time. Similarly, there are a tremendous number of personal narratives about the experiences of living with HIV/AIDS. Such personal accounts deserve greater attention - particularly in terms of how people with HIV/AIDS have represented themselves through alternative media projects.

Looking ahead, there are several ideas for future research that follow from this project. For instance, during the course of this project, there has been an increase in the use of the internet among AIDS activists (and political activists in general). Each of the media projects in this study, for instance, have expanded to include an internet version of their publication. *POZ*, *Body Positive*, and the *BCPWA News* are now published on a website. *The Positive Side*, *Diseased Pariah News*, and *Treatment Information Flash* in contrast have been discontinued, in part, because of the increased use of the internet as a form of communication. As a new frontier in alternative media, the way in which the internet is being used by those in AIDS organizations, by groups, and by individuals with HIV/AIDS is an issue that deserves

to be examined in more depth. Such a project might look critically at how the internet is being presented to people as a resource and how people are using the internet as a resource.

This project focused on the perspective of those involved in media projects. This approach meant that it was difficult to know how people used and read alternative media projects. In fact, as I have noted, this question created a crisis for many of those involved in the production of publications that were designed to be by and for people with HIV/AIDS. In media studies there have been more research on audiences. This perspective could be valuable in order to understand how alternative media projects has been used and read by people with HIV/AIDS. Such a study could look at print media as a resource or how people interpret or analyze the material represented in publications like *POZ* or *DPN*. Such a study would provide greater insight into the limitations of print media as a form of communication within the context of social movements.

Lastly, shifting away from the community based response to HIV/AIDS, it would be valuable to look at the increasing use of alternative media in general. For instance, a study might examine how those involved in various social movements in health are making use of alternative media - both print and electronic. Beyond health, a similar study could look at the use of media among activists in general. From another perspective, it would also be interesting to examine the use of alternative media, especially zines and the internet because they are the most accessible, among those who are not involved in or associated with a social movement. Such a study might explore the reasons why people make the decision to start producing their own media rather than using or relying on the mass media.

Implications for the Use of Alternative Media as a Form of Activism

This reseach was not conducted in order to making recommendations about the use of alternative media. However, it is evident that there are several lessons that stem from the analysis that might be of use to those involved in alternative media projects. In working closely with people involved in PWA media it would be rewarding if this research did have a positive impact on their continued efforts.

The use of alternative media in the context of political organizing appears to be on the rise, particularly as people gain more access to media technologies. There are some indications that print media in the form of newsletters have even become too widespread, at least in the area of HIV/AIDS. Government agencies that fund community-based organizations are beginning to ask whether it is really necessary to have, for example, eighteen different publication on treatments for HIV/AIDS. Nonetheless, media projects are still being developed by groups of people with HIV/AIDS in particular on the margins of the organized HIV/AIDS community in the form of zines similar to *DPN*. Similarly, people with HIV/AIDS are turning to electronic media - particularly video and the internet - as the next frontier of media activism. This shift toward electronic media appears to be prevalent among those working in AIDS organizations and among those who are more on the margins of the organized HIV/AIDS community. Given this trend, there are several suggestions that can be made that are based on this study about the use of media among those involved in or associated with community or political organizing.

1. In terms of developing projects, one of the central findings in this study is that AIDS organizations have played a key role in supporting and nurturing print media by and

for people with HIV/AIDS. In many cases, organizations provided the resources needed to start and sustain a publication. There were occasions when change in organizational structure led to the discontinuation of a media project. But, in these cases the projects were likely to have been impossible to initiate without the support of an AIDS organization. Social movement organizations, in general, could play a greater role in supporting grassroots forms of media activism, particularly in order to divert funds from the state to community-based projects. At a time when the monopoly over mass communication continues to escalate, it would be beneficial if organizations helped to create the opportunity for greater involvement in alternative media projects.

2. Alternative media projects could play a greater role as forums for those who feel silenced but have a desire to be heard. The print media in this study have given many people with HIV/AIDS an opportunity to express their own perspective on living with HIV/AIDS. In many cases, writing about their experiences helped them to make sense of what it means to be a person with HIV/AIDS. The value of such forums is not limited to HIV/AIDS. Indeed, they could be extended to, for example, the expression of illness experience in general. There have been several books and anthologies that feature the stories of people who used writing as a means of making sense of their health problems. However, not everyone has the skills or the resources needed to write their own book. A media project like a journal or a website on illness narratives would provide an accessible and alternative forum for a wider group of people interested in writing about their experiences.

3. As an increasing number of people begin to use alternative media, there is a danger that the political aspects of such communication will be incorporated into the power structures that control the mass media. Such attempts at containment would limit the potential for media projects to be subversive in the way they are produced and in what they represent. In the case of print media by and for people with HIV/AIDS, there does appear to be a trend toward incorporation and containment - by the state through control over funding, by AIDS industries through advertising, and by the mass media by adopting a more subtle and sensitive approach to representing HIV/AIDS. In response, alternative media projects need to sustain, as much as possible, a politically subversive stance toward the material that is published and the strategies used to produce this material - to challenge convention . The danger is that the status of being 'alternative' will become controlled by those who are threatened by media activism rather than by those who are involved in such projects. People involved in alternative media projects will need to exercise greater care in using resources, particularly from government and industry, in a strategic way so as to not give up control.

4. The rhetoric surrounding new media technologies attests to their democratic potential to create wider access to communication. On one level, it is possible that the internet, for example, could open new potentially democratic spaces for people to become more actively involved in the decisions that affect their lives. However, it is more likely that the internet will become dominated by e-commerce and that public participation will be pushed to the margins. Often the talk about the potential

of new media technologies is greater in scope than what is actually possible. Media

projects by and for people with HIV/AIDS have served as public forums, but only

to an unknown degree. It arguable that *POZ* or *Body Positive* are really intended for

those involved in the organized HIV/AIDS community. The extent to which they

reach beyond this group remains a mystery. One more hopefully sign is that many

physicians are beginning to leave *POZ* in their waiting rooms for their patients. The

situation for smaller projects like *The Positive Side* is even more uncertain. For those

involved in alternative media, access needs to be treated as an ongoing problem.

More conscious attention should be devoted to using alternative media as a form of

community development and greater efforts could be made to address the gap

between those involved in producing media projects and those who are, or could be,

drawing on and using this material.

BIBLIOGRAPHY

Adam, B. (1987). The Rise of a Gay and Lesbian Movement. Boston: G.K. Hall Press.

Adam, B. (1992). "Sociology and People Living with AIDS." In J. Huber & B. Schneider (Eds.), The Social Context of AIDS. Newbury Park: Sage Publications.

Adam, B. & Sears, A. (1996). Experiencing HIV: Personal, Family, and Work Relationships. New York : Columbia University Press.

Aggleton, P. (1996). "Identity and audience: Living with HIV disease." International Studies in Sociology of Education, 6, 2, 211-224.

Albert, A. (1986). "Acquired immune deficiency syndrome: the victim and the press." Studies in Communication, 3, 135-58.

Altman, D. (1982). The Homosexualization of America. Boston: Beacon Press.

Altman, D. (1986). AIDS in the Mind of America. New York: Double Day Press.

Altman, D. (1993). "Expertise, Legitimacy, and the Centrality of Community." In P. Aggleton, P. Davis, & G. Hart (Eds.), AIDS: Facing the Second Decade. London: Falmer Press.

Altman, D. (1994). Power and Community: Organizational and Cultural Responses to AIDS. London: Taylor and Francis.

Anzaldua, G. (1990). Making face, Making Soul/Haciendo Caras: Creative and Critical Perspectives by Women of Colour. San Francisco: Aunt Lute Foundation Books.

Ariss, R. (1993). "Performing anger: Emotion in strategic responses to AIDS." Australian Journal of Anthropology, 4, 1, 18-30.

Ariss, R. (1996). Against Death: The Practice of Living with AIDS. Australia: Gordon & Breach Publishers.

Alonzo, A. & Reynolds, N. (1995). "Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory." Social Science and Medicine, 41, 3, 303-315.

Armstrong, D. (1981). A Trumpet to Arms. Boston: South End.

Arno, P. (1986). "The nonprofit sector's responses to the AIDS epidemic: Community-based services in San Francisco." American Journal of Public Health, 76, 1325-1330.

Arno, P. & Hughes, R. (1989). "Local Policy Responses to the AIDS Epidemic: New York and San Francisco." In P. Imperato (Ed.), AIDS: Public Policy Dimensions. New York: Plenum Medical Books.

Austin, S. (1990). "AIDS and Africa, United States media and racist fantasy." Cultural Critique, 14, 129-141.

Baker, A. (1986). "The Portrayal of AIDS in the Media: An Analysis of Articles in the New York Times." In D. Feldman & T. Johnson (Eds.), The Social Dimensions of AIDS: Method and Theory. New York: Praeger.

Barnes, D., Taylor Brown, S. & Wiener, L. (1997). "I didn't leave y'all on purpose: HIV infected mothers' videotaped legacies for their children." Qualitative Sociology, 20, 1, 7-32.

Barroso, J. (1997). Reconstructing my life: Becoming a long term survivor of AIDS." Qualitative Health Research 7, 1, 57-74.

Bayor, R. (1989). Private Acts and Social Consequences: AIDS and the Politics of Public Health. New York: Free Press.

Bayer, R. (1991). "Covering the plague: AIDS and the American media." AIDS Education and Prevention, 3, 1, 74-86.

Bayer, R. & D. Kirp, (1992). "The United States: At the Center of the Storm." In Kirp, D. & R. Bayer (Eds.), AIDS in the Industrialized Democracies. Montreal: McGill-Queen's University Press.

Becker, H. (1967). The Other Side. New York: Free Press.

Belsey, C. (1980) Critical Practice. London: Methuen.

Berridge, V. (1983). "AIDS: History and Contemporary History." In G. Herdt & S. Lindenbaum (Eds.), The Time of AIDS: Social Analysis, Theory, and Method. New Bury Park: Sage.

Berridge, V. & Strong, P. (1993). AIDS and Contemporary History. Cambridge: Cambridge University Press.

Bersani, L. (1988). "Is the Rectum a Grave." In D. Crimp (Ed.), AIDS: Cultural Analysis, Cultural Activism. Boston: MIT Press.

Blumer, H. (1955). "Collective Behavior." In R. Park (Ed.), An Outline of the Principles of Sociology. New York: Barnes & Noble.

Bourdieu, P. (1996). "Understanding." Theory Culture and Society, 13, 2, 17-37.

Brieger, W. (1990). "Media and health communication in rural Nigeria." Health Policy and Planning, 5, 1, 77-81.

Brown, M. (1997). Replacing Citizenship: AIDS Activism and Radical Democracy. New York: Guilford Press.

Buxton, R. (1991) "After it happened...: The battle to present AIDS in television drama." Velvet Light Trap, 27, 37-48.

Cain, R. (1993a). AIDS Service Organizations in Context. Hamilton: McMaster University. Unpublished Research Report.

Cain, R. (1993b). "Community-based AIDS services: Formalization and depoliticalization." International Journal of Health Services, 23, 4, 665-686.

Cain, R. (1994). "Managing impressions of an AIDS service organization: Into the mainstream or out of the closet?" Qualitative Sociology, 33, 2, 43-71.

Callen, M. (1987). "Founding Statement of People with AIDS/ARC: The Denver Principles." In M. Callen (Ed.), Striving and Thriving with AIDS: Collected Wisdom. New York: People with AIDS Coalition, Inc.

Callen, M. (1990). Surviving AIDS. New York: Harper Collins.

Cancian, F. (1993). "Conflicts between activist research and academic success: Participatory research and alternative strategies." The American Sociologist, Spring, 92-106.

Carpenter, N. (1988). "AIDS initiatives in Massachusetts: Building a continuum of care." New England Journal of Public Policy, 4, 1, 429-440.

Carter, G. (1992). ACT UP, the AIDS War and Activism. New Jersey: Open Magazine.

Carter, E. & Watney, S. (1989). Taking Liberties: AIDS and Cultural Politics. London: Serpent's Tail.

Catalan, J. & Pugh, K. (1995). "Suicidal behaviour and HIV infection: Is there a link?" AIDS Care, 7, 2, S117-S121.

Chambre, S. (1991). "Volunteers as witnesses: The mobilization of AIDS volunteers in New York City, 1981-1988." Social Service Review, 65, 4, 531-547.

Clarke, J. (1991). "Media portrayal of disease from the medical, political economy, and lifestyle perspective." Qualitative Health Research, 1, 3, 287-308.

Clarke, J. (1992). "Cancer, heart disease, and AIDS: what do the media tell us about these disease." Health Communication, 4, 2, 105-120.

Clarke, J. (1993). "Burlington Breast Cancer Support Services." Waterloo: Wilfrid Laurier University: Unpublished Manuscript.

Clausson, N. (1989). AIDS: The community-based response. Canadian Journal of Public Health. 80, S18-S20.

Cleary, P. (1993). "Living and dying with AIDS." New England Journal of Medicine, 328, 6, 450.

Cohen, J. (1991). "The 'relevance' of cultural identity in audiences' interpretations of mass media." Critical Studies in Mass Communication, 8, 4, 442-454.

Counter, M. (1996). "A history of the people living with HIV/AIDS (PLWHA) movement in Australia." Social Alternatives, 15, 4, 25-27.

Cowles, K. & Rodgers, B. (1997) "Struggling to keep on top: Meeting the everyday challenges of AIDS." Qualitative Health Research, 7, 1, 98-120.

Crawford, R. (1994). "The boundries of the self and the unhealthy other: Reflections on health, culture and AIDS." Social Science and Medicine, 38, 10, 1347-1365.

Crimp, D. (1988). AIDS: Cultural Analysis, Cultural Activism. Boston: MIT Press.

Crimp, D. & A. Rolston, (1990). AIDS DEMO GRAPHICS. Seattle: Bay Press.

Crossley, M. (1997). "Survivors and victims: Long term HIV positive individuals and the ethos of self empowerment." Social Science and Medicine, 45, 12, 1863-1873.

Cunningham, I. (1989). "The public controversies of AIDS in Puerto Rico." Social Science and Medicine, 29, 4, 545-553.

Davies, M. (1997). "Shattered assumptions: Time and the experience of long term HIV positivity." Social Science and Medicine, 44, 5, 561-571.

Dean, R. (1995). "Stories of AIDS: The use of narrative as an approach to understanding in an AIDS support group." Clinical Social Work Journal, 23, 3, 287-304.

Denzin, N. (1992). Symbolic Interactionism and Cultural Studies. Oxford: Blackwell.

Downing, J. (1984). Radical Media. Boston: South End Press.

Downing, J. (1988). "The alternative public realm: The organization of the 1980s anti-nuclear press in West Germany and Britain." Media Culture and Society, 10, 163-181.

Dreifus, C. (1970). Seizing Our Bodies: The Politics of the Women's Health Movement. New York: Vintage.

Dunbar, H., Mueller, C., Medina, C., & Wolf, T. (1998) "Psychological and spiritual growth in women living with HIV." Social-Work 43, 2, 144-154.

Durbar, H. & Mueller, C. (1995/6). "Women and HIV: The process of transcendence." Arete, 20, 2, 6-15.

Dworkin, S. & Wachs, F. (1998). "Disciplining the body": HIV positive male athletes, media surveillance, and the policing of sexuality." Sociology of Sport-Journal, 15, 1, 1-20.

Eckholdt, H., Chin, J., Manzon-Santos, J., Kim, D. (1997). "The needs of Asians and Pacific Islanders living with HIV in New York City." AIDS Education and Prevention, 9, 6, 493-504.

Eley, G. (1992). "Nations, Publics, and Political Cultures: Placing Habermas in the Nineteenth Century." In C. Calhoun (Ed.), Habermas and the Public Sphere. Cambridge: MIT Press.

Epstein, S. (1991). Democratic science? AIDS activism and the contested construction of knowledge. Socialist Review, 21, 2, 35-64.

Erni, J. (1992). "Articulating the (im)possible: Popular media and the cultural politics of curing AIDS." Communication, 13, 1, 39-56.

Felski, R. (1989). "Feminism, postmodernism an the critique of modernity." Cultural Critique, 13, 33-56.

Fraser, N. (1992). "Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy." In C. Calhoun (Ed.), Habermas and the Public Sphere. Cambridge: MIT Press.

Gamson, J. (1989). "Silence, Death, and the Invisible Enemy: AIDS activism and social movement newness." Social Problems, 36, 4, 351-367.

Garnham, N. (1987). "The Media and the Public Sphere. In P. Golding, G. Murdock, & P. Schlesinger (Eds.), Communicating Politics: Mass Communications and the Political Process. New York: Holmes & Meier.

Godin, G., Savard, J., Kok, G., Fortin, C., & Boyer, R. (1996). "HIV seropositive gay men: Understanding adoption of safe sexual practices." AIDS Education and Prevention, 8, 6, 529-545.

Gillman, R. & Newman, B. (1996). "Psychosocial concerns and strengths of women with HIV infection: An empirical study" Families in Society, 77, 3, 131-141.

Glasner, B. & Strauss, A. (1967). The Discovery of Grounded Theory. Chicago: Aldine.

Gramsci, A. (1983). "Hegemony (Civil Society) and the Separation of Powers." In A. Mattelart & S. Siegelaub (Eds.), Communication and Class Struggle: Liberation, Socialism. New York: International General.

Graubard, S. (1990). Living with AIDS. Cambridge: MIT Press.

Green, G. & Platt, S. (1997). "Fear and loathing in health care settings reported by people with HIV." Sociology of Health and Illness, 19, 1, 70-92.

Greene, K. & Serovich, J. (1996). "Appropriateness of disclosure of HIV testing information: The perspective of PLWAs." Journal of Applied Communication Research, 24, 1, 50-65.

Gronfors, M. & Stalstrom, O. (1987). "Power, prestige, profit: AIDS and the oppression of homosexual people." Acta Sociologica, 30, 1, 53-66.

Habermas, J. (1979). "The Public Sphere." In A. Mattelart & S. Siegelaub (Eds.), Communication and Class Struggle: Capitalism, Imperialism. New York: International General.

Habermas, J. (1989). The Structural Transformation of the Public Sphere. Cambridge: MIT Press.

Hackl, K., Somlai, A., Kelly, J., Kalichman, S. (1997). "Women living with HIV/AIDS: The dual challenge of being a patient and caregiver." Health and Social Work, 22, 1, 53-62.

Hall, S. (1980). "Cultural studies: Two paradigms." Media, Culture and Society, 2, 57-72.

Hassin, J. (1994). "Living a responsible life: The impact of AIDS on the social identity of intravenous drug users." Social Science and Medicine, 39, 3, 391-400.

Herzlich, C., Pierret, J., & Mellott, N. (1989). "The construction of a social phenomenon: AIDS in the French press." Social Science and Medicine, 29, 11, 1235-1242.

Hunt, A. (1992). "Productive living strategies for people with AIDS." AIDS Care, 4, 3, 353-355.

Johnson, R. (1986/7). "What is cultural studies anyway?" Social Text, 16, 38-80.

Kahn, A. (1993). AIDS: The Winter War. Philadelphia: Temple University Press.

Kalichman, S., Sikkema, K., & Somlai, A. (1996). "People living with HIV infection who attend and do not attend support groups: A pilot study of needs, characteristics and experiences." AIDS Care, 8, 5, 589-599.

Kawata, P. (1989). "Community-Based Response to AIDS." In V. Harden & G. Risse (Eds.), AIDS and the Historian: Proceedings of a Conference at the National Institutes of Health Washington: National Institutes of Health.

Kayal, P., (1993). Bearing Witness: Gay Men's Health Crisis and the Politics of AIDS. Oxford: Westview Press.

Kessler, L. (1984). The Dissident Press. Beverly Hills: Sage.

Kessler, L., Silvia, A., Aronstein, D., & Patton, C. (1988). "Call to action: A community responds." New England Journal of Public Policy, 4, 1, 441-453.

King, D. (1990). "Prostitutes as pariah in the age of AIDS: A content analysis of coverage of women prostitutes in the New York Times and the Washington Post September 1985 - April 1998." Women and Health, 16, 3/4, 155-176.

Kinsman, G. (1987). The Regulation of Desire: Sexuality in Canada. Montreal: Black Rose Press.

Kinsman, G. (1992). "Managing AIDS organizing: 'Consultation,' 'partnership,' and the National AIDS Strategy." In W.K. Carroll (Ed.), Organizing Dissent: Contemporary Social Movements in Theory and Practice. Toronto: Garamond Press.

Kirp, D. & Bayer, R. (1992). AIDS in the Industrialized Democracies: Passions, Politics, and Policies. Montreal: McGill-Queen's University Press.

Kitzinger, J. (1990). "Audience understanding of AIDS media messages: A discussion of methods." Sociology of Health and Illness, 12, 3, 320-335.

Knapper, K. (1991). "Media activism and difference." Socialist Review, 2, 109-121.

Leonardis, O. & Mauri, D. (1992). "From deinstitutionalization to the social enterprise." Social Policy, 25, 3, 50-54.

Lester, E. (1992). "The AIDS story and moral panic: How the Euro-African press constructs AIDS." Howard Journal of Communications, 3, 3-4, 230-241.

Lupton, D. (1994). Moral Threats and Dangerous Desires: AIDS in the News Media. London: Taylor & Francis.

MacLachlan, J. (1992). "Managing AIDS: A phenomenology of experiment, empowerment and expediency." Critique of Anthropology, 12, 4, 433-456.

Mancoske, R., Wadsworth, C., Dugas, D., Hasney, J. (1995). "Suicide risk among people living with AIDS." Social Work, 40, 6, 783-787.

Marger, M. (1984). "Social movement organizations and response to environmental change: The NAACP, 1960-1973." Social Problems, 32, 16-30.

Marshall, B. (1991). "Communication as politics: Feminist print media in English Canada."

Women's Studies International Forum, 18, 4, 463-474.

McCain, N. & Gramling, L. (1992). "Living with dying: Coping with HIV disease." Issues in

Mental Health Nursing, 13, 3, 271-284.

Meyer, P., Tapley, E., & Bazargan, M. (1996). "Depression in HIV symptomatic gay and

bisexual men." Journal of Gay and Lesbian Social-Services, 5, 4, 69-85.

McCormick, W., Hopkins, S., Wood, R., Wood, C., Deyo, R., & Inui, T. (1993). The Seattle

appropriate level of care survey: Health status and health services use in ambulatory

persons with AIDS." AIDS Care. 5, 3, 369-378.

McLaughlin, L. (1993). "Feminism, the public sphere, media and democracy." Media, Culture

and Society, 15, 599-620.

McLuhan, M. (1964). Understanding Media: The Extensions of Man. London: Routledge.

Melucci, A. (1989). Nomads of the Present. Philadelphia: Temple University Press.

Miller, J. (1992). Fluid Exchanges: Artists and Critics in the AIDS Crisis. Toronto: University

of Toronto Press.

Morris, A. & Mueller, C. (1992). Frontiers in Social Movement Theory. New Haven: Yale

University Press.

Negt, O. & A. Kluge. (1983). "The Proletarian Public Sphere." In A. Mattelart & S. Siegelaub

(Eds.), Communication and Class Struggle: Liberation, Socialism. New York:

International General.

Nelkin, D. (1991). "AIDS and the news media." The Millbank Quarterly, 69, 2, 293-307.

New, M. & Trickett, S. (1998). "Community support to families living with HIV in London:
An agency overview. AIDS Care, 10, 2, 191-196.

O'Brien, M. (1992). Living with HIV: An Experiment in Courage. New York: Auburn House.

Padgug, R. & Oppenheimer,G. (1992). "Riding the Tiger: AIDS and the Gay Community."
In E. Fee & D. Fox (Eds.), AIDS: The Making of a Chronic Disease. Los Angeles:
University of California Press.

Palombi, L., Mancinelli, S., Liotta, G., Narciso, P., & Marazzi, M. (1994). "Health and
functional status on survival in a sample of AIDS patients." AIDS Care, 9, 6, 671-680.

Patton, C. (1985). Sex and Germs: The Politics of AIDS. Boston: South End Press.

Patton, C. (1990). Inventing AIDS. New York: Routledge, Chapman and Hall.

Pawluch, D., Cain, R., & Gillett, J. (1994). Ideology and alternative therapy use among people
living with HIV/AIDS. Health and Canadian Society, 2, 1, 63-84.

Pearl, A. & Riessman, F. (1965). New Careers for the Poor. New York: Free Press.

Petras, E. & D. Porpora. (1993). "Participatory research: Three models and an analysis. The
American Sociologist, Spring, 107-126.

Piven, F. & Cloward, R. (1977) Poor People's Movements. New York: Vintage Books.

Pueschel, K. & Heinemann, A. (1995). "HIV and suicide in Hamburg." AIDS Care, 7, 2,
S129-S134.

Rabkin, J., Remien, R., Katoff, L., & Williams, J. (1993). "Suicidality in AIDS long term
survivors: What is the evidence?" AIDS Care, 5, 4, 401-411.

Rank, F., Marshall, R. and Parlavecchio, R. (1992). The emergence of an HIV/AIDS
community in W.A. National AIDS Bulletin, October, 15.

Rayside, D. & Lindquist, E. (1992). "Canada: Community Activism, Federalism, and the New Politics of Disease." In Kirp, D. & R. Bayer (Eds.), AIDS in the Industrialized Democracies: Passions, Politics, and Policies. Montreal: McGill-Queen's University Press.

Reardon, K. & Richardson, J.(1991). "The important role of mass media in the diffusion of accurate information about AIDS." Journal-of-Homosexuality, 21, 1-2, 63-75.

Riano, P. (1994). Women in Grassroots Communication. London: Sage.

Roberts, T. (1995). "African American gay males with HIV/AIDS: Building upon cultural capacities to survive." Journal of Gay and Lesbian Social Services, 2, 3-4, 75-87.

Rodriguez, N. (1988) "A successful shelter: A case study of the family crisis shelter in Hawaii." Journal of Applied Behaviour Science, 24, 235-250.

Ross, M. & Carson, J. (1988). "Effectiveness of distribution of information on AIDS: A national study of six media in Australia." New York State Journal of Medicine, 239-241.

Roy, C. (1995). Living & Serving: Persons with HIV in the Canadian AIDS Movement. Ottawa: Canadian AIDS Society.

Sacks, V. (1996). "Women and AIDS: An analysis of media misrepresentations." Social Science and Medicine, 42, 1, 59-73.

Sandstrom, K. (1996). "Redefining sex and intimacy: The sexual self images, outlooks, and relationships of gay men living with HIV/AIDS." Symbolic Interaction, 19, 3, 241-262.

Slavin, H. (1994). "Positively women: Living with AIDS." Feminist Review, 47,102-103.

Schatzman, L. & Strauss, A. (1973). Field Research. Englewood Cliffs: Prentice Hall.

Schechter, S. (1982). Women and Male Violence: The Visions and Struggles of the Battered Women's Movement. Boston: South End Press.

Schneider, B & Huber, J. (1992). "Introduction." In J. Huber & B. Schneider (Eds.), The Social Context of AIDS. Newbury Park: Sage Publications.

Sears, A. (1991). "AIDS and the health of nations: The contradictions of public health." Critical-Sociology, 18, 2, 31-50.

Seeger, A. (1987). "An unreported class war: Ideology and self-censorship on the *Berkeley Barb*." Communication, 10, 1, 31-50.

Segal, L. (1989). "Lessons from the Past: Feminism, Sexual Politics and the Challenge of AIDS." In E. Carter & S. Watney (Eds.), Taking Liberties: AIDS and Cultural Politics. London: Serpent's Tail.

Shernoff, M. (1997). "Gay men with AIDS in rural America." Journal of Gay and Lesbian Social Services, 7, 1, 73-85.

Siegel, K., Karus, D. & Raveis, H. (1997). "Testing and treatment behaviour of HIV infected women: White, African American, Puerto Rican comparisons." AIDS Care, 9, 3, 297-309.

Simon, J., Mason, H., Marks, G., Ruiz, M., & Richardson, J. (1995). "Women living with HIV: Sexual behaviours and counselling experiences." Women and Health, 23, 4, 17-26.

Smith, G. (1990). "Political activist as ethnographer." Social Problems, 37, 4, 629-648.

Smith, M. (1993). "Feminist Media and Cultural Politics." In P. Creedon (Ed.), Women in Mass Communication. London: Sage.

Sontag, S. (1989). AIDS and Its Metaphors. London: Anchor Books.

Staggenborg, S. (1988). "The consequence of professionalization and formalization in the pro-choice movement." American Sociological Review. 53, 585-606.

Stevenson, N. (1995). Understanding Media Cultures. London: Sage.

Stroman, C. & Seltzer, R. (1989). "Mass media use and knowledge of AIDS." Journalism Quarterly, 66, 4, 881-887.

Thomas, C. (1996). "The HIV athlete: Policy, obligations, and attitudes." Sport Science Review, 5, 2, 12-29.

Trend, D. (1993). Rethinking media activism: why the left is losing the cultural war. Socialist Review, 2, 5-33.

Treichler, P. (1987). "AID, Homophobia, and Biomedical Discourse: An Epidemic of Signification." In D. Crimp (Ed.), AIDS: Cultural Analysis, Cultural Activism. Boston: MIT Press.

Trussler, T. & R. Marchand, (1993). Taking Care of Each Other: Health Promotion in Community Based AIDS Work. Vancouver: AIDS Vancouver.

Watney, S. (1987). Policing Desire: AIDS, Pornography, and the Media. London: Methuen.

Weber, M. (1949). The Methodology of the Social Sciences. New York: Free Press.

Weeks, J., (1989). AIDS: The Intellectual Agenda. In P. Aggleton, G. Hart, & P. Davies' (Eds), AIDS: Social Representations-Social Practices. (pp.1-20) London: Falmer Press.

Weitz, R. (1984). "From Accommodation to Rebellion: The Politicalization of Lesbianism. In T. Darty & S. Potter (Eds.), Women-Identified Women. Palo Alto: Mayfield.

Weitz, R. (1990). "Living with the stigma of AIDS." Qualitative Sociology, 13, 1, 23-38.

Weitz, R. (1991). Life with AIDS. New Brunswick: Rutgers University Press.

Whittaker, A. (1992). "Living with HIV: Resistance by positive people." Medical Anthropology Quarterly, 6, 4, 385-390.

Whyte W. (1995). "Encounters with participatory action research." Qualitative Sociology, 18, 3, 289-299.

Wilkinson, S. & Kitzinger, C. (1993). Whose breast is it anyway? A feminist consideration of advice and "treatment" for breast cancer. Women's Studies Forum, 16, 3, 229-238.

Williams, R. (1977). Marxism and Literature. Oxford: Oxford University Press.

Winnow, J. (1992). "Lesbians' evolving health care: Cancer and AIDS." Feminist-Review, 41, 68-76.

Withorn, A. (1980). "Helping ourselves: The limits and potential of self-help." Social-Policy, 11, 3, 20-27.

Zola, I. (1987). "The politicization of the self-help movement." Social-Policy 18, 2, 32-33.