NEW SOCIAL MOVEMENTS

IN CANADIAN HEALTH DOMAIN:

AIDS SASKATOON AS A CASE STUDY

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ABSTRACT

AIDS Saskatoon, considered as a health social movement, is the focus of this research. It uses notions of life-world, system and life-world colonization as well as the typology of politics introduced by Cohen and Arato to answer the questions:

- Why did AIDS Saskatoon emerge?
- Is AIDS Saskatoon a defensive or an offensive social movement?

The defensive movement's action is directed inward to the lifeworld and civil society, while the offensive modes of movement activism directed outward to state and economic institutions. With regards to the first question, I argue AIDS Saskatoon was formed as a reaction to patterns of the colonization of the life-world of people living with HIV/AIDS. Relative to the second question AIDS Saskatoon is seen to be a creative response to the colonization process that takes an organizational form conducive to both defensive and offensive dimensions.

Data for this study were derived from ten qualitative interviews were conducted - five with individuals diagnosed HIV/AIDS positive, three with the AIDS Saskatoon administrative staff, and two with the founders of AIDS Saskatoon.

ACKNOWLEDGEMENTS

DEDICATION

Say (O Muhammad): "He is Allāh, (the) One. Allāh (The Self-Sufficient Master, Whom all creatures need, He neither eats nor drinks). "He begets not, nor was He begotten; "And there is none co-equal or comparable unto Him." (112:1-4)

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CHAPTER ONE: BACKGROUND

1.1 Introduction

Little attention has been paid to social movements organized around health-related issues within Canadian society. This is despite the eminent role that the health social movements play in a society and, as Brown *et al*. (2004) put it, social movements dealing with health are very important influences on our health care system and a major force for change in the larger society. Additionally, the study of the impacts that health social movements have on the health, political and social systems, as Sidney (1999) notes, is one of the most neglected topics in the literature. The lack of scholarly work on this topic within the Canadian context is all the more unfortunate if we take into account the fact that one of the fundamental reasons for social movements' existence is to bring about changes in some aspects of society. In this study I aim to underscore this basic goal of health movements, which is often acknowledged but not often addressed clearly, as well as attempting to come up with an understanding of how health social movements emerge by taking AIDS Saskatoon as a case study. Based on some recent studies which were mainly conducted in the United States (Epstein, 1996; Brown *et al*., 2004), we come to know that health social movements not only challenge state structures but also aim to redefine the sets of social relations that presuppose such structures and the symbolic elements that justify them. More importantly, social movements in the health domain can have an institutional impact both on the political level and on the social and cultural level.

Studying health social movements is appealing because they are a fundamental component of contemporary societies and because they are a major factor for the articulation of underrepresented political interests. Sidney (1999) suggests that if we are

to understand how movements contribute to social change, we need to provide answers to questions of the strength and direction of change. How durable are the changes brought about by social movements? Are these effects mostly positive or mostly negative for both the society and the movements themselves? These two questions have often been framed in terms of the institutional impact of movements and in terms of the contributions of movements to democracy. Brown *et al*. (2004) argue that there seems to be at least three main ways in which health social movements affect society. First, they produce changes in the health care and public health systems, both in terms of health care delivery and social policies and regulations. Second, they produce changes in medical science, through the promotion of innovative research, and changes in funding priorities. Third, many health social movements produce changes in civil society by pushing to democratize those institutions that shape medical research and policy-making. As for the question of the direction of the changes produced by social movements, this study explores the role health social movements play as a force for democratization and emancipation of society. However, for the purpose of developing an analytical framework to pursue this inquiry, the dual concept of offensive/defensive that has been used within the literature of new social movements is employed for finding out the types of activities, the forms and direction of the changes brought about by AIDS Saskatoon, in other words exploring the position AIDS Saskatoon is claiming within Canadian civil society. Habermas (1981) employed the concept of defensive /offensive to draw the line between new social movements that have positive potential in pushing the project of modernity forward and the movements that do not have this potential. Cohen and Arato (1992) extended the concept of offensive/defensive social movements and linked it to a typology of politics.

These theoretical revisions are discussed in more details below.

In regard to the question of how new social movements come about Eyerman and Jamison (1991) consider a number of approaches used by sociologists to understand the rise of new social movements in the twentieth century and note how particularly unsatisfactory the explanations offered for the student movement of the 1960s have been. In this research, two major theoretical approaches to social movements are discussed: resource mobilization theory and new social movements theory.

Habermas' approach, which is considered to be a significant branch of new social movement theory and upon which this research relies for developing a framework to account for the rise of new social movements, is discussed in more detail in a separate section.

1.2 AIDS Movements Historical Background

AIDS organizations emerged as social movements in the early 1980s. In North America, AIDS groups first grew out of the homosexual movements and began to involve progressive health care workers. They developed as social movements as a response to the state's inaction and indifference to problems with medical professions and to social discrimination against homosexuals, injection drug users, and sex trade workers (Carroll, 1992).

The activism of people with AIDS fighting for their lives led to unprecedented changes in the health care system including: accelerating drug trials, pharmaceutical price reductions, large increases in AIDS research and funding, and fighting insurance rate increases.

<h3 style="text-align:center">1.3 AIDS Saskatoon Overview</h3>

All the information introduced in this section is taken primarily for AIDS Saskatoon's statements and policies. The purpose of this section is to give an overarching idea about AIDS Saskatoon' history and its policy and the work it does.

1.3.1 AIDS Saskatoon's History

AIDS Saskatoon is the primary community based AIDS organization in central and northern Saskatchewan. It was founded in 1986, as a community-based, harm reduction organization. It is dedicated to providing support, prevention, and education for both the people infected and affected by HIV/AIDS, including the community at large. AIDS Saskatoon is committed to a holistic, collaborative and inclusive approach to the work it does with individuals, organizations, and communities.

AIDS Saskatoon's vision is that all people living with, affected by, and vulnerable to HIV/AIDS get the care and support they need in a comfortable, accessible, and respectful setting, are not discriminated against, are able to make informed choices and have access to personal and community resources to prevent new HIV infections.

1.3.2 AIDS Saskatoon's Policy

One of the eminent elements of AIDS Saskatoon's policy is to be free of any sort of preconceived ideas or judgments about people with whom they meet and work. AIDS Saskatoon holds that all people have the right to participate in a community of mutual respect and dignity in order to be able to develop a safe community encompassing a dynamic blend of physical, emotional and spiritual security. AIDS Saskatoon recognizes that the compounded realities of poverty, classism, racism, social isolation, past trauma, sex-based discrimination, and other social inequalities affect both people's

vulnerability and capacity to deal with HIV/AIDS and other life challenges.

AIDS Saskatoon is committed to working with individuals and communities to challenge the individual and systemic discrimination and oppression of people who are marginalized. AIDS Saskatoon works to ensure that people with HIV/AIDS have a real voice in the creation of programs and policies designed to serve them.

1.3.3 AIDS Saskatoon's Services

AIDS Saskatoon offers workshops and presentations in schools, community centers, workplaces and healthcare settings, to people of all ages, and from diverse backgrounds of life in central and northern Saskatchewan. AIDS Saskatoon operates a local phone line and province wide toll-free information line and also maintains a resource centre with a lending library, video collection and research documents. AIDS Saskatoon works with and provides support for persons living with the HIV infection and their families, friends and loved ones.

1.4 Research Background and Questions

Health social movements are significant social phenomena which need to be studied and understood, particularly in how they come about, what role they play and what effect they bring about within contemporary societies. The fact that hundreds of HIV positive patients go, interact and affiliate with such organizations means that social movements are functional and that their existence has a purpose. Moreover, there must be plausible reasons for those peoples' inclination to seek help from such organizations rather than other official health care establishments. In view of the fact that a lot of people with HIV/AIDS turn away from the established health system and seek help and support from health movement organizations, means there must be some problems

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occurring. Communication problems and lack of understanding might be some of them. When we look at the findings of this case study the same question can be asked. Since people with HIV/AIDS affiliate with this organization, it is plausible that AIDS Saskatoon satisfies real needs and provides necessary support and services.

This research hypothesises that people with AIDS affiliate and support AIDS Saskatoon because their lifeworld has been colonized by the system, the communicative actions have been distorted, and also because such organizations provide them with a space where they can speak about their experiences, share thoughts, gain mutual understanding and build up a collective identity.

Habermas, in his defense for the program of modernity which he describes as an unfinished project, talks about a legitimacy crisis within the welfare state. Accordingly, he believes this crisis to be deepening as a result of the continuous growth of instrumental rationality which he thought to be impeding the processes of democratization and emancipation in the civil society. According to his theory this gives rise to social movements that resist such unjust consequences. However, he distinguishes between defensive movements which are reactionary responses by traditionalist groups, and offensive movements which are more progressive resistance by groups that seek a rational reconstruction of the lifeworld, such as some elements of the feminist movement. From these two perspectives stem the two main questions for this research:

- howhealth social movements come into being?
- is AIDS Saskatoon an offensive or defensive type of movement?

To answer these questions I used Habermas' theory of communicative action as a framework to account for the emergence of AIDS Saskatoon as a health social

movement. In particular I used the concepts of lifeworld, systemworld and the colonization of the lifeworld to guide my inquiry. Second, the typology of politics introduced by Cohen and Arato is employed to find out whether AIDS Saskatoon is a defensive or offensive movement, and for examining the role of AIDS Saskatoon as a force of emancipation and democratization within Canadian civil society.

1.5 The Importance and Significance of Study

Personally, many years before getting a chance to live in any western country such as Canada, probably since I was in the first year of my undergraduate studies, I have had an interest in understanding the western system. Democracy, civil society and economic prosperity were the main broad topics that I have always wanted to understand, specifically the way they operate, interact and develop. I think studying social movements through the work of Habermas will ultimately lead to understand how these three essential pillars of the western system work.

Academically, this study allows an understanding of how health issues are subject to social, economic and political processes and gives a deeper understanding of contemporary social movements in the Canadian health domain. It also explores and highlights the interconnectedness of population, organizations, science and public policies, as well as exploring and highlighting the potential of health social movements as a major force of change in civil society.

In summary this research aspires to enhance understanding of the conditions that result in the emergence of such movements, and to increase understanding of how such movements contribute to the democratization and emancipation of Canadian society.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Social movements have been described as expressions of the dynamism of civil society; one of the driving forces for social change. The term 'social movement' denotes any group or network of groups with common beliefs and actions pursuing or resisting selected social changes ranging from better material rewards for certain jobs to the extension of civil rights and political influence (Crossley, 2003).

Over the last half of the Twentieth century, the number and variety of social movements increased. It is only within the past 35 years, however, that they have begun to receive systematic attention within the field of sociology. Over that period, studies of social change have displaced structural-functional approaches which assumed that social stability and harmony were the normal state. Consequently, social scientists no longer view social movements as threatening and irrational; rather they are seen as normal and rational political challenges of aggrieved groups (Kozinets & Handelman, 2004).

In the 1960s and 1970s a silent revolution in European and American societies gave rise to social movements that articulated 'post-material' values (Martin, 2001). Although the new social movements build upon the accomplishments of 'old' social movements, such as the labor movement, they are less concerned with the 'old' issues of material well-being and more concerned with 'new' cultural issues and struggles over the meaning and quality of life (Singh, 2001; Martin, 2001). In other words, while the 'old' social movements emanated from the class structure of industrial capitalism and aimed at addressing the material inequalities produced by the capitalist mode of production, the 'new' social movements cut across classes and are guided by non-material

considerations. Offe (1985) sees the new social movements as being new in that they are not addressing the same problems as the 'old' social movements that were embedded within class struggle. The liberal democratic states had learned to accept the old movements in the form of trade unions and collective bargaining and the various forms of the welfare state to achieve social control and manage conflicts in the wider political sphere.

2.2 Social Movement Concept

In this section I outline, discuss, and compare two major theoretical approaches to social movements; resource mobilization theory and new social movement theory. Habermas' approach, which is a major branch of the latter, will be discussed in more detail in a separate section. The purpose of this section is to identify an appropriate approach for studying new social movements in the health domain.

Current debates of social movements focus on issues such as the nature of new social movements, and the distinctions between social movements and political parties, and interest groups. Traditional definitions of social movements identified them as any set of non-institutionalized collective actions consciously oriented towards social change or resisting such changes and possessing a minimum of organization (Wilkinson 1971: 27; Turner & Killian 1972: 246). Blumer (1969) observes that social movements arise from a condition of unrest and derive their motivational power from dissatisfaction with the current form of life and from wishes and hopes for a new system of living. Porta and Diani (1999) define social movements as informal networks based on shared beliefs and solidarity which mobilize around conflictual issues and deploy frequent and varying forms of protest. Tilly (1984:3 06) defines social movements as 'sustained series of

interactions between power holders and persons successfully claiming to speak on behalf of a constituency lacking formal representation, in the course of which those persons make publicly visible demands for changes in the distribution or exercise of power, and back those demands with public demonstrations of support'. Melucci (1989: 29) proposes a definition of social movements as collective phenomena which contain three dimensions; a form of collective action, conflict, and the ability to break the limits of the system. He considers typical of social movements only those actions that challenge the mechanisms of systemic domination. These definitions are intended to enable social movements to be distinguished from various forms of collective actions which are more structured and which take on the form of parties, interest groups or religious sects, as well as single protest events.

In contrast with some public interest groups and sects social movements actors come together with different identities and orientations and develop a sense of belongingness, and a shared system of beliefs while maintaining their specificity and distinctive characters. Mario (1992) argues that collective actions that take a form of a protest against the construction of a highway run by informal citizens' groups, or a demonstration for better nursing facilities in a neighborhood can not be considered part of a social movement. Some have suggested looking at the scope, dimension and length of campaigns (Marwell and Oliver, 1984; Turner and Killian, 1987) in making this distinction. Periodic or short duration collective behavior guided mainly by impulse cannot be regarded as a social movement. However, when short-lived impulses give way to long term aims, and when sustained association takes the place of situational groupings of people, the result is a social movement.

The definitions introduced above highlight defining characteristics of social movements. Habermas's approach to new social movements, however, has the intention of pushing forward the emancipatory and progressive aspects of the project of modernity. According to Habermas social movements

- arise at the seam ands express the tension between lifeworld and system

- have a long history of collective identity and action

- are concerned with the quality of life.

2.3 Theoretical Approaches

It is generally thought that there are three periods in the sociological study of social movements. In the first period, a social psychological approach was dominant and social movements were seen as negative and irrational behaviors. The second period saw social movements from the perspective of theories of collective behavior and attributed a more positive social role to them (Tilly, 2004). The third and current period is characterized by two competing theories: the first one is the European new social movement approach and the second is the North American perspective identified as resource mobilization theory (Holst *et al*., 2002). Both attempt to explain the emergence and the significance of contemporary social movements in post industrial societies. In doing so, both approaches have reformulated traditional theories of collective action on each side of the Atlantic. The theoretical issues each perspective addresses are largely determined by the different scientific traditions and contemporary debates in each region. The new social movement theory, for instance, questions reductionist Marxism that assigned to the working class a privileged place in the unfolding of history. The resource mobilization theory, in contrast, criticizes Durkheim's view of collective action as

anomic and irrational behaviors resulting from rapid social change, and it questions the 'relative deprivation' theory which assumes a direct link between perceived deprivation and collective action. Each perspective developed in relative isolation from the other and, with little theoretical interaction between them (Carroll, 1992).

2.3.1 Resource Mobilization Theory

Traditionally, the fundamental question in the field of sociology had been how to explain individuals' participation in social movements' activities. The key traditional paradigms, such as relative deprivation (Morrison 1978), collective behavior (Wilkinson 1971) and mass society theory (Kornhauser 1959), pointed to sudden increases in individual grievances generated by the 'structural strains' resulting from rapid social change. These traditional theories also shared the assumptions that movement participation was relatively rare, movement and institutionalized actions were sharply distinct, and movement actors were not rational (Jenkins, 1983). The movements of the sixties dramatically challenged these assumptions. By providing a rich array of experience and enlisting the active sympathies of an enlarged group of analysts, the movementss stimulated a shift in theoretical assumptions and analytic emphases that eventually became formalized in the resource mobilization theory of social movements (Jenkins, 1983). The resource mobilization theory emerged in the seventies and became the dominant paradigm for studying social movements because it was better able to account for the sixties cycle of protest than previous traditional theories (Buechler, 1993). As Simsek, (2004) points out, the leading proponents of this theory are Charles Tilly, Anthony Oberschall, John McCarthy and Mayer Zald. The central orienting premise of the resource mobilization theory is that the emergence and persistence of social

movement activity is contingent on the availability of resources that can be channeled into movement mobilization and activity. In other terms, McCarthy and Zald hypothesize that there is a direct link between resource availability and movement emergence; that is, the greater the absolute amount of resources available, the greater the likelihood that new social movements will develop (Snow *et al*., 2005).

According to resource mobilization theorists, to succeed in changing mainstream society, social movements must secure resources from both inside and outside their organizations. These resources can include not only financial or material capital such as money, space, equipment, but also human capital such as knowledge, volunteer effort and social capital networking potential, and organizational resilience (Nerbonne and Nelson, 2004). Resource mobilization theory adopts the rational choice theory's approach, a school of thought which maintains that social life in general is characterized by individuals who act to maximize the satisfaction of their interests and to avoid undue risks. Their consequential assumption is that individuals' preferences and outcomes can be predicted given their basic interests, the consequences they face and the strategies of broader political games (Byrd, 1999).

This framework of analysis can be challenged for its focus on self-interest as the main motive leading to participation in social movements, which therefore amounts to little more than associations of individuals calculating the costs and benefits of their action. Therefore, resource mobilization theory has only partially contributed to our understanding of how people get recruited into organized social action. As a result, the need to address the question as to how contemporary social movements came into being cannot be adequately met by a reliance on resource mobilization theory alone.

2.3.2 New Social Movement Theory

The new social movement theory proposed by sociologists like Touraine (1992), Melucci (1980), and Habermas (1981) appeared as an alternative to the resource mobilization paradigm. It emerged in Europe as a critique of Marxism's economic determinism. According to Buechler (1993) this approach is, in large part, a response to the economic reductionism of classical Marxism that failed to adequately grasp contemporary forms of collective action. The discontent created by modernization, industrialization, nationalization and centralization combined with the failure of the socialist experiment in the Soviet Union, paved the way for new ideological, socio-economic and cultural endeavors (Simsek, 2004). The new social movement theorists think about social movements in relation to some societal totality. In many new social movements' theoretical formulations, such as those of Touraine (1992) and Habermas (1981), new social movements are cast as historically specific responses to the totalizing and hegemonic cultural forms defined by capitalist markets, administration, and welfare state (Kozinets *et al*., 2004). These interrelated new capacities for self-transformation and social change have received a central place in the sociological theorizing of the new social movement theorists. Especially within European studies, a wide variety of different new social movement theorists have deployed concepts relating politics and culture to the contexts of contemporary social movements. In an overview article, Buechler (1995) places the theories of Touraine, Melucci and Habermas as central to the large body of new social movement theorizing. Positioning their approach in relation to the economic reductionism of classical Marxism, these new social movement theorists look to logics of action based not within the sphere of production but in the spheres of politics, ideology

and culture. In addition, they look for sources of collective identity such as ethnicity, gender and sexuality to complement the Marxist predilection for class-based identity (Kozinets *et al.*, 2004).

Melucci (1980) represents in his theory the interdependence of these three elements; politics, ideology and culture in a social movement. Melucci also argues that new social movements are identity-based rather than class-based (Martin, 2001).

Habermas (1981) links new social movements to conflicts that deviate from the welfare-state pattern of institutionalized conflict over distribution. New social movements are, according to him, concerned with the grammar of forms of life and engaged in conflicts around the quality of life, equality, individual self-realization, participation and human rights. He argues that such conflicts should be understood as resistance to tendencies to colonize the life world, and are aimed at revitalizing buried possibilities for expression and communication (Ruggiero, 2000).

New social movement theorists accurately point out that contemporary social movements such as peace and ecologic movements share identities and goals that are historically new in relation to older social movements (Cohen, 1985). New social movement theories stress the symbolic and cultural spheres (Kivisto, 1986; Crook *et al.*, 1992). They argue that instead of forming unions or political parties, new social movements form grassroots coalitions within the domain of civil society. They also maintain that new social movements raise issues concerned with the democratization of structures of "the grammar of forms of life" and focus on communication and collective identity (Habermas, 1984; Touraine, 1985).

Proponents of the new social movement theory criticize the resource mobilization

paradigm most frequently and radically on the grounds that it neglects the cultural dimension of social movements. They argue that cultural and symbolic aspects of life are inseparable from the strategies, tactics and ways of organization, which constitute the main themes of concern for the proponents of the resource mobilization theory (Simsek, 2004).

2.3.3 Habermas and New Social Movements

Habermas theorizes the rise of new social movements as a response to both the 'colonization of the lifeworld' and 'cultural impoverishment' characteristic of modernizing societies. To fully understand these conditions we must first discuss his theory of communicative action.

Habermas argues that social well-being depends on a critical balance between the social processes that reproduce cultural traditions, social integration and personal identities, on one hand, and activities related to the administration and execution of power on the other (Crossley, 2004). In his view, modern societies consist of these two worlds; the first realm is a background context that he calls the lifeworld, in which people construct, and maintain meanings, and the second, which include administration, welfare state, and economic system is called systemworld. In his theory of communicative action he distinguishes cognitive-instrumental rationality, and communicative rationality. An instrumental rationality takes precedence over forms of reasoning that take into account two neglected realms that are essential for the construction of meaning in life as well as for social harmony: the aesthetic and the ethical. As instrumental rationality is applied to more and more spheres of the everyday life, subjecting everything in its path to management aiming at greater control, we do get fascinating and powerful new

technologies. But people themselves are not exempt from this will to objectify and control. The extension of instrumental rationality into more and more spheres of life brings about what Habermas calls a colonization of the lifeworld. This affects several processes that serve to restore and renovate the lifeworld across the generations. It disrupts the transmission and critique of cultural knowledge and values, creating what Weber recognizes as a loss of meaning (Crossley, 2004). Colonization takes place when the instrumental rationality invades the lifeworld; in other words the administration, welfare state, and economic system with its market mentalities infiltrating into other areas of life. When that happens, relationships based on communication (which foster understanding, trust and solidarity) are replaced by relationships based on instrumental ends, wherein the interaction is steered by the media of money and power (which foster exactly the opposite). Habermas believes that this fact accounts for all the major "pathologies" of the contemporary world. Habermas thinks that there is such a crisis, and it is deepening. The reason is that the media 'money and power' are non-communicative. What he means is that in such condition whoever has the most wins and that would be the end of process. There is no possibility of reaching a common understanding through these media (Habermas, 1979).

This research takes the position as White (1989) puts it that Habermas provides the most suitable argument to account for the rise of new social movements, and also the best framework for understanding the behavior of new social movements and the work they do. The system-lifeworld distinction is the hallmark of Habermas' general theory and it is no less crucial for understanding his theory of new social movements and their ability to generate a public sphere (Gemma, 2004). His arrangement in regard to social

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movements is that they are a response of the lifeworld colonization processes (Scott, 1990) and, as a consequence, to "cultural impoverishment" (Habermas, 1981). The colonization of the lifeworld refers to a penetration of economic and political systems which have become uncoupled from the lifeworld back into it in a corrosive way. Colonization in its economic form, for instance, entails the uncoupled market mechanism extending further into the lifeworld, eroding cultures and replacing traditional (communicative) forms of social interaction and relationships with (self-interested) financial transactions. This imposes functional rationality on lifeworld interactions (Habermas, 1981), distorting them with the system-steering media money and power, and creating 'new' conflicts and tensions surrounding culture, identity and lifestyle (Gemma, 2004). From this condition stems what Habermas terms as cultural impoverishment because economic transactions cannot fulfill the important symbolic functions performed by tradition and communicative engagement such as the reproduction of a sense of identity and purpose. It is a process that leads to turning active citizens into clients who receive their due benefits but do not have a share in the discussion of public issues. Consequently it causes to the decline of public sphere, capability of the lifeworld to perform the socially integrative functions, and to a diminution of communicative actions.

These processes of colonization, impoverishment and the decline of the public sphere, would lead to the rise of the new social movements as responsive actions to restore such unbalanced situations. This may make the new movements sound reactionary, and Habermas believes that some of them are. However, he is clear to distinguish between reactionary responses by traditionalists like ('Not In My Back Yard') movement and more progressive resistance by groups that seek a rational reconstruction

of the lifeworld such as feminist movements. Colonization processes, therefore, provide new sources of struggle and change in agents seeking to defend traditional lifestyles or institute new ones on their own terms (Habermas, 1981).

2.4 Offensive and Defensive Movements

Habermas (1984) emphasizes the fact that new social movements seek no material compensation from the welfare state. He argues that new social movements can be of a defensive nature, as they attempt to shield endangered ways of life from further systemic colonization. And as a result of this defensive nature of the new social movements, Habermas contends that new social movements, except for the feminist movement which has a clear emancipatory potential, are not well positioned for promoting institutional change within civil society and developing the positive potentials of modernity. However, and as Cohen (1995) puts it, Habermas' dualistic conception of society implies that new social movements are open to both defensive struggles to protect and democratize the communicative infrastructure of everyday life and offensive projects of radical institutional reform.

Cohen and Arato (1992) take Habermas' formulation a step further in offering a clearer distinction between defensive action directed inward to the lifeworld and civil society, and offensive modes of movement activism directed outward to state and economic institutions. In this recasting the 'defensive' aspect involves preserving and developing the communicative infrastructure of the lifeworld, through redefining identities, reinterpreting norms, developing egalitarian and democratic associational forms and securing institutional changes within civil society that correspond to the new meanings, identities, and norms that are created (Cohen and Arato, 1992). The

'offensive' aspect targets political and economic society, the realms of mediation between civil society and the subsystems of the administrative state and the economy and struggles not only for resources and political recognition but for influence with regard to political insiders and for institutional reform (Cohen and Arato, 1992).

2.5 Typology of Politics

In this context, Cohen and Arato (1992) introduce some classifications with respect to new social movements' way of operating that can be of a good benefit to this research, particularly in understanding the direction AIDS Saskatoon has been undertaking in regard to its overall operational activities since the day it was established through all its development stages up until this time.

Cohen and Arato (1992) introduce a model which comprises four different forms of political strategy practiced by new social movements: the politics of identity, influence, inclusion and reform. Their understanding of the politics of identity which correspond with the defensive mode of the movement stands for "the redefining of cultural norms, forming individual and collective identities, appropriating social roles, and the form of discourses" (1992, p 45) this differs from Habermas' view in that the development of new associations and a communicative infrastructure within the lifeworld is understood as democratization of civil society and emancipation. The politics of inclusion target political institutions to gain recognition for new political actors as members and to achieve benefits for those whom they represent (Cohen, 1995). The politics of influence aim at altering the universe of political discourse to accommodate new interpretations, new identities and new norms (Cohen, 1995). The final element in the model, the politics of reform, denotes the attempts made by new social movements to

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alter the structure and functioning of the formal systems of economy and state.

This research holds the position that AIDS Saskatoon is a type of movement that tends to undertake an organizational form conducive to both defensive and offensive dimensions.

2.6 AIDS Activism Literature Review

Recently more attention is being paid to health social movements, such as the AIDS movement, by medical sociologists and social movement specialists, and the study of those movements is taking rapid steps in countries like the United States (Epstein 1996, Hoffman, 2003, Brown *et al.*; 2004) and the UK (Weeks *et al.*; 1996, Berridge,2002, Allsop *et al.*, 2004), producing a significant body of literature which is helping in reducing a big gap that has been left wide open for a long time in this area of research. This gap comes as a result of two contradictory factors. As Brown *et al.* (2004) put it many medical sociologists have studied such movements without reference to social movement theory and literature, while social movement specialists rarely take up issues of health.

Within the Canadian context the state of this area of inquiry is even more unfortunate and thus a lot of work needs to be done to fill the gap. However there are some important works that were done in Canada about AIDS activism which are partially relevant to this study as it is explained below, such as the work of Sears (1991), Emke (1992), Maguire *et al.* (2001), and Romanow (2003).

In this section I discuss two papers that are most relevant to this study: Sears (1991) and Emke (1992). Employing the Foucauldian formula of power/knowledge, both highlight the ongoing struggle among the official health system, the state and community

based groups. Both researchers argue that AIDS activists in community based groups are exerting a wide variety of efforts to restore people's control over their bodies and lives and encounter power imbalance created by the state. Sears (1991, p. 32), in his study discusses two conflicting trends; the first is the politics of health from above in which the state plays an instrumental role and views public health officials as experts that dispassionately accumulate information on health threats and possess the necessary knowledge to protect the populace. The second trend is health from below, through which those whose well being is at stake acquire the main role by increasing their power over the resources, knowledge and thus the ability to make choices for their well being.

Confidential HIV testing advocated by the first trend versus anonymous testing adopted by the latter is effectively used by Sears (1991, p. 43) to illustrate the conflicting nature between sides, the position each trend is taking and their supporting arguments. Public health officials, proponents of confidential HIV testing, claim that the state must know the names of those who test positive to perform basic epidemiological tracking, to provide officials with information on who is infected as the basis for intervention and analysis, and thus halt the spread of infection and assist those already infected. Moreover, confidential testing is crucial because it allows officials to locate people who test positive but do not go back to find out the result of their test, and prevents the same person being tested more than once would not be reported as multiple.

Anonymous testing on the other hand, in which results are not linked to names, is seen as crucial by community based groups because it is serves the needs of those at risk for HIV infection so they would not be hesitant to get tested and know whether or not they contracted the disease. These groups also point out the fact that people who consider

themselves at risk for HIV avoid getting tested when their names are reported to health authorities for fear that their sex partners will be traced and informed. Furthermore, they argue that those who are tested anonymously will be more open to talk about sensitive personal information such as high risk activities, problems in informing sex partners, and will be more ready to explore solutions. Likewise, they are more likely to discuss illegal activities such as banned drug use in an anonymous context.

Sears cites Bayer (1989) and Connor (1989), stating that it is not the fear of leaks that motivate these groups to oppose reportable confidential testing "which is still a concern", but more importantly these groups mistrust state control and see it as an obstacle to people taking control over their health. They see that doctors, by reporting back to health authorities, become an extension of state power over people who are infected. Sears (1991, p. 47) concludes that the conflict over confidential as opposed to anonymous testing is just one of the many instances in which the politics of AIDS activism come into conflict with those of public health.

Emke (1992, p. 58) is taking the same approach yet focuses on a different aspect to illustrate the power struggle between medical authorities and patients. He concentrates particularly on the medical authority's obsession with patient compliance and the organized and purposive resistance of patient groups, specifically AIDS activists, in the light of the theoretical assumption that such an activity is a political and therapeutic strategy for reclaiming power over the medicalized body. The author points out that social expectation to obey medical authority are a fairly recent phenomenon. Before medical domination was in place people consulted a range of medical practitioners both lay and official for their advice and then decided whether or not to follow the healer's

suggestions.

The research shows how the claim that medicine is a uniform body of knowledge that can speak authoritatively on all manner of human weakness and that it should be given an unquestioned powerful status is being attacked and challenged by AIDS activism. Patient non-compliance is employed by Emke (1992, p 61) to illustrate the power knowledge conflict between the two sides, about which officials take the position that non-compliance undermines the doctor-patient relationship. Furthermore, they see it as patient reticence, ignorance or recalcitrance, rather than doctor miscommunication or the inappropriate managing of a power imbalance. Community based groups on the other hand argue that the demand for compliance represents an ideology which reinforces a particular set of power relations. They also doubt that strict compliance would always have positive health outcomes with those that have chronic conditions, where compliance may result in serious side effects.

AIDS activism's refusal to accept the passive roles of patient and medical consumer can be seen as a form of non-compliance with the medical system, and the manifestation of that can be seen in the way AIDS activists have been questioning the methods by which medical research is done. For example, they are opposing the scientists' claim that randomized, double-blind, placebo-controlled clinical trials are the only valid way to collect reliable evidence on the efficacy of a drug. And thus they argue that using placebos in the testing of a drug that has already shown some promise is unethical. Emke (1992, p. 64) states "There are widespread but anecdotal accounts of non-compliant research subjects who might join a study and then pool their drugs so that every one is assured of getting at least some of the active agent". Through buyers' clubs,

activists monitor drug research, make contacts for promising pharmaceuticals even before they have been approved, import drugs if necessary and sell them to those infected. In some cases activists even provided access to medications that were not yet licensed for use. The research concludes that activities of the AIDS groups are not only rejection of the passive subject positions of patients, but also taking steps to rectify the power imbalance between healers and patients.

Although Sears (1991) and Emke (1992) offer a deep understanding of the conflicting nature between AIDS activism and health authority, power relation, and the tactic each side is using in this conflict. Both researchers do not recognize AIDS activism as a form of social movement and also both scholars have not examined the forces that gave rise to AIDS activism as new health social movement. Both themes are considered to be the main factors for conducting this research.

CHAPTER THREE: METHODOLOGY

3.1 Research Design and Methods

Given the nature of this inquiry, qualitative research design was the most appropriate approach. The qualitative methodological approach provided means to inspect a social phenomenon's development through available local history documents, and in-depth interviews and also enabled the researcher to place the study in a cultural context (Cresswell, 1998). Such in-depth analysis would not be possible using quantitative methods. In order to know how AIDS Saskatoon came into being it was important to look at the starting point of its history, thus the movement's archives as well as relevant local history documents were examined.

3.2 Interview Procedures

 Semi-structured interviews were used for two main reasons: to minimize the researcher's influence on participants' responses, and to ensure the interview remained focused on the research questions. The open ended questions that are listed in section 3.4 are used as main themes to start the interviews and were not the only ones asked. All interviews were audio-taped and later transcribed in full.

Silverman (1993) suggests detailed transcripts are an essential corrective to the limitations of intuition and recollection and they enable repeated examination thus extending the range of observations. Participants were contacted through a key person from the AIDS Saskatoon administration. Purposefully selecting recognized valuable informants enables one best to answer research questions (Creswell, 1994). Patton (1990, p. 169) elucidates:

> The logic and power of purposeful sampling lies in selecting information
> rich cases for in-depth study. Information-rich cases are those from which

one can learn a great deal about issues of central importance to the purpose of the research.

3.3 Target Population of the Research

The target population of the research is the key members of AIDS Saskatoon's administrative staff, the founders of the organization, and people with HIV/AIDS affiliated with AIDS Saskatoon.

The number of people interviewed was not specified at the beginning of the project, although 12 to 15 interviews was a rough target. I was able to reach saturation point by conducting 10 interviews, five with HIV/ AIDS positive individuals, three with the members of the administration, and two with the founders of the AIDS Saskatoon. Because of the fact that AIDS Saskatoon is a small organization and the number of interviewees is very small, I am taking very strict measures to protect participants' confidentiality. Thus, I am avoiding using pseudonyms that may identify the gender of the participant so it would be easy to distinguish the identity of the founders or the members of the administration in particular. Instead the participants are numbered in the following way;

- The founders of AIDS Saskatoon are Participant number 1 and Participant number 2.

- The key administration members are Participant number 3, Participant number 4 and Participants number 5.

- Those who are HIV/AIDS positive and affiliated with AIDS Saskatoon are Participants number 6, 7, 8, 9, and 10.

For the same confidentiality measures the terms HIV and AIDS are used alternatively when talking about those who are HIV positive, although they denote two different stages

of the disease

3.4 Analytical Framework and Interviews Questions

This research addresses two issues - the emergence of AIDS Saskatoon as a health social movement, and whether AIDS Saskatoon is an offensive or defensive type of movement. Thus, the analysis is presented in two sections. The first explains the approach taken to explore the relationship between the colonization of the lifeworld and the existence of AIDS Saskatoon. The second explains the approach to investigate the type of politics AIDS Saskatoon is undertaking and therefore whether it is an offensive or defensive type of movement.

3.4.1 Section 1: Colonization Patterns

This section examines the colonization of the lifeworld of people affiliated with AIDS Saskatoon. The basic question is how can we identify the colonization of the lifeworld of people with AIDS who participated in the case study?

Based on findings from previous studies, mostly conducted in the United States and England (Barry *et al*., 2001, Hoffmam, 2003, Scambler, 2001, Beck, 1992, Brodeur, 1985), the following themes were used to identify the colonization of the people with AIDS' lifeworld.

a) Doctor patient relationships

Mishler's (1984) ideas about the struggle between the voice of medicine and the voice of the lifeworld give a good way for looking at doctor patient communication. It shows that in the system of technological medicine strategic action is used to maintain profession dominance. This strategic action takes the form of distorted communication

patterns oriented to controlling patients and achieving medically preferred goals. He

illustrates how physicians employ manipulative techniques in the consultation to keep

control of the dialogue. As a result, communication was carried out almost completely in

the voice of medicine and the voice of the lifeworld was suppressed. This form of

communication fits very well with Habermas' ideas about the system rationalization and

colonization of the lifeworld. It could be said that doctors are using consciously or

unconsciously distorted communication in a success oriented, purposive rational action

(Barry *et al.,* 2001). In such case communication is distorted because it is conducted

under the influence of technical power.

For this theme the focus was on finding out whether the voice of medicine is

taking over the voice of the lifeworld. The following questions were used as main themes

for conducting the interviews:

1- How often do you see your doctor since you have been diagnosed with HIV?

2- How long do your meetings with the doctor usually last?

3- Do you get a chance to explain your condition?

These questions can be a good indicator of doctor patient miscommunication, meaning

that when voice of medicine is taking over the voice of lifeworld, patients do not get

chances to explain themselves and as a result of that meeting duration is shrunk, and

frequency of these kinds of meetings is reduced.

The following questions can give a clear indication of communication level

between doctors and patients. If the patient's opinion is taken into consideration, he/she

will be satisfied with his/her doctor's decision, and thus he/she will abide with the

doctor's instruction and trust him or her, or otherwise he/she will not. The following

questions were used for conducting the interviews:

4- Do you think that your opinion about your condition is taken into
consideration by your doctor?

5- Do you feel satisfied with your doctor's decisions regarding your condition?

6- Do you abide with your doctor's instructions?

7- Do you trust your doctor?

b) Drug and insurance companies

In the United-States, as Hoffmam (2003) points out, ACT UP, the radical

organization of people with AIDS founded in 1987, at first protested against health and

disability insurance companies with HIV exclusions in their policies. But even when

some of this blatant discrimination was eliminated, most people with AIDS still could not

get access to private insurance because of its extraordinarily high cost. A committee

related to this movement in California launched a publicity campaign featuring a poster

that read "lack of insurance kills people with AIDS" - lack of insurance means lack of

access to health care, and lack of health care means death (Hoffman, 2003, p. 83).

The focus for this theme is on finding out how the economic system is invading

the lifeworld and turning citizens into clients of the welfare state. The following

questions were used as main themes for conducting the interviews:

1- Have you ever faced any difficulties getting access to any type of health
insurance?

2- Have you experienced any sort of discriminations by insurance companies?

3- Have you had any difficulties getting access to any medical services?

4- Have you had any difficulties getting access to any social services?

5- Have you been able to afford the cost of your medication?

Asking these questions was helpful in exploring the result of excluding the public from health policy making, and also in knowing how marginalised groups do not have the same chance as the other parts in society.

c) Medicalization of social problems

Scambler (1987), in his essay 'Habermas and the power of medical expertise', discusses how through the process of medicalization, many public health conditions and situations have been taken out of the public sphere. Scambler's example in explaining this phenomenon is built around the experience of childbirth, but other conditions such as the menopause, infertility and hyperactivity have all been seen as examples of 'medicalization', or the removal of issues from discussion in the public sphere, where questions of a moral-practical nature might be asked. In introducing his argument that medical knowledge, based as it is in science and technology, has come to overpower the lay knowledge of childbirth possessed by women, suggests that this can be seen as an example of the colonization of the lifeworld. Using Habermas' theory, these could all be understood as cases in which the limited purposive-instrumental rationality which dominates expert systems colonizes the lifeworld. The values and concerns as well as the communicative interactive style of reaching mutual understanding definitive of a communicative rationality are set aside, and expert practitioners decide on treatments and what counts as successes.

The focus for this theme is on how the media of money and power displace communicatively rational actions, that is, how medical knowledge overpowers and displaces lay knowledge. The following questions were used as main themes for

conducting the interviews:

1- What are the aspects of this sickness that are well known by the patients but not by the doctors?

2- What are the aspects that should be kept for the patients to decide about?

3- Does your knowledge about your condition come mostly from your own experience or from other sources?

4- Have you had any role in deciding about your treatment?

d) Increasing scientization:

Technical solutions are now provided instead of social solutions regarding health and social polices. Science and technocratic decision-making have become an increasingly dominant force in shaping social policy and regulation. Governmental and scientific demands for better science in policy-making have become a significant and powerful authority used to support dominant political and socioeconomic systems (Beck, 1992). The result of this process is excluding public or "patients" from important policy debates, participating in decision-making and ensuring that it becomes the purview of experts (Weinberg, 1972).

The focus for this theme is on how science and technocratic decision-making have become an increasingly dominant force in shaping social policy and regulation thus excluding the public including patients from important policy debates.

1. How would you describe the possibilities of your being part of any health related policy making process?

2. Did it happen that you as an organization got invited or somehow involved in any policy debate related to AIDS issues?

3. Have you ever worked for creating such an opportunity?

e) Biomedical abuses:

Brodeur (1985) points out the manner in which science and medicine are used as instruments of coercion; in military medicine and corporate medicine, health professionals supposedly serving their patients' interests are in reality serving their institutions' requirements, at the expense of the patients. For instance, company physicians in the asbestos industry hid from workers the information that they had mesothelioma caused by asbestos (Brodeur 1985, p. 46). This theme is used to know if AIDS Saskatoon through out its history has noticed any misuse of medical authority by the public health professions.

Questions:

1. Have you ever noticed or received a complaint regarding a misuse of medical authority to your members

3.4.2 Section 2: Types of Politics

The part focuses on the effects health social movements bring about within the Canadian society, and as it is stated above, under this inquiry comes the question of what role AIDS Saskatoon may have as a force of change, democratization, emancipation and hence whether AIDS Saskatoon could be an offensive or defensive type of movement.

In order to be able to examine these aspects, the typology of politics Cohen and Arato (1992) discuss guided the development of interview questions in several ways. First, the Politics of identity (which corresponds to defensive mode) includes the redefinition of cultural norms. The main points here are related to the role social movements may have in:

- Reacting to social interactions that stigmatize chronically ill people and blame them for their conditions;

- Amplifying the voices of people most affected and influencing social attitudes to be changed;

- Operating as a pressure group on medical authorities as well as government authorities for reconstructing policies.

Interviews questions:

1. Describe the reaction of those with whom you have been in contact since you were diagnosed with HIV?

2. Have you ever participated in a group discussion regarding AIDS?

3. Have you participated in mobilization activities or rallies?

Second, the politics of identity involves forming individual and collective identities, and empowering individuals with new knowledge and support. The main points here include:

- Generating spaces where people can come together for mutual support and to raise awareness about issues affecting their lives;

- Because social movements are often formed by marginalized people, by coming together around a common issue, they can provide mutual support and a sense of solidarity. For people living with HIV and AIDS, this support can help to shape a positive meaning to a positive diagnosis;

- Communication for social change puts people at the centre of their own change, setting their own priorities, finding their own ways of communicating and organizing;

- Creating opportunities for people to learn from the successes and failures of others and deepening their understanding of how communication can help change their ideas

about their condition.

Interview questions relating to these themes were:

1. When did you start coming to AIDS Saskatoon?

2. How often do you come to AIDS Saskatoon?

3. How often do you meet with others in AIDS Saskatoon?

4. Describe your relationship with other members of AIDS Saskatoon?

5. How deeply do you get to know others?

6. Have you learned anything new through other people's experiences?

7. Have you offered support of any sort to others and have you received any?

A third dimension includes appropriating social roles (offering different types of help). The main point here is about the way social movements react to major social problems, such as HIV, that have impacts on many aspects of life like sexuality, social inequality, health and psychological problems and financial difficulties.

The associated interview questions were:

1. Do you get any financial help from AIDS Saskatoon?

2. Does AIDS Saskatoon offer any psychological consultations to its member?

3. Does AIDS Saskatoon offer any health consultations to its member?

The fourth component of the politics of identity entails forming discourses, offering a space for people to talk, share their experiences and reach mutual understanding. The focus here is on the role social movements have in:

- Creating autonomous spaces outside the structures of the state where people come and talk and develop their confidence, skills, solidarity and strength towards achieving their objectives;

- Promoting participatory communication processes in which people most affected are talking directly to each other or to their peers, rather than being talked about by a third party;

- Creating a space for dialogue between people which can support them in making informed and relevant decisions about how to live their lives.

The relevant interviews questions were:

1. How often do you participate in group discussions?

2. Do you have a regular meeting for the members?

3. What are the mostly discussed topics?

4. Have you benefited from any dialogue or discussion in taking any decision in regard to your condition?

5. What is your objective for being an AIDS Saskatoon member?

b) The Politics of inclusion (corresponding to offensive mode) stands for targeting political institutions to gain recognition for new political actors as members and to achieve benefits for those whom they represent.

The following questions were used to explore these themes:

1. Do you have any supporters inside the political institution at the provincial level?

2. As an organization, how would you describe your relationship with the health care system?

3. Do you have any members who are involved in politics?

c) The Politics of influence (corresponding to the offensive mode) aims at altering the universe of political discourse to accommodate, new interpretations, new identities, and

new norms.

Associated questions were:

1. Have you succeeded in putting forward new positive ideas in regard to people with AIDS?

2. Have you participated in any mobilization activities?

3. Have you won any legislative victories?

d) The Politics of reform (corresponding to the offensive mode) denotes new social movements attempting to alter the structure and functioning of the formal systems of economy and state. This can be seen through the outcomes of the AIDS Saskatoon's various activities and also by leveling its work in the other types of politics.

The main points to be looked at here are the role AIDS Saskatoon plays in.

- Expanding the public sphere.

- Changing the public discourse.

- Offering a kind of public sphere within the movement itself by creating a space for discourse for those who are not heard by the system.

- Members of this social movement penetrated the state itself in order to launch reform projects.

Interviews questions:

1. How would you evaluate the work of your movement in terms of changing the mainstream ideas and stereotypes regarding people with AIDS?

2. As an organization, how would you describe your relationship with the political system?

3.5 Collecting and Analyzing Data

In terms of the data collecting process, I started by initiating visits to AIDS Saskatoon so I got a chance to familiarize myself with the place and people and their daily routine. During these visits I met some members of the administration, who were very friendly and supportive of the project. One of them kindly agreed to recruit participants for the project to be interviewed and she/he was very helpful in terms of offering a suitable place for conducting the interviews

The interviews were semi-structured with open-ended questions that allowed the researcher to have in-depth discussion with the participants. Explaining the exploratory nature of the study helped in making participants understand that I wanted to hear about their experiences in general and not about certain events in particular. The first interviews were done with the founders of the movement and secondly with those who were HIV positive, and finally with members of the administration. All the interviews were done in AIDS Saskatoon facilities except for one which was done outside of Saskatoon in the house of one of the founders of Aids Saskatoon.

With participants' permission, interviews were recorded on a digital recording device and later transcribed in full. The transcribed interviews produced 12 hours of taped conversation and 214 pages of text. The average length of each interview was one hour and 12 minutes.

Data analysis is a continuous process (Singleton and Straits, 1999) so the analysis process started right after each interview. Following each interview, I listened to the audio recording and made some initial notes. I read through each transcript multiple times to identify key phrases and also used the taped interview records to capture tone and emphasis. Silverman (1993) recommends that the interviewer pay attention to the inner

voice – the true thoughts and feelings of the participant. In this study arranging for the first meeting with each participant before starting the actual interviews helped in establishing rapport and trust with participants so that during the interview itself they felt comfortable enough to talk freely and share their thoughts. Based on my theoretical framework, interviews were coded into themes and then interpreted and classified as they emerged from the data. Each stage of coding involved further examination of previous steps and each time a new theme became evident, the original data was reviewed to find examples of that theme. The data within each theme were then compared and analyzed to make sure all quotations were properly categorized.

3.6 Data Collection Difficulties

1. One participant is living outside of Saskatoon so I had to travel to meet him/her there at her/his house.

2. AIDS Saskatoon was going through some changes in terms of its administration; key members were busy so it took quite a long time to get the interviews done.

3. Some participants do not have contact information so it was kind of struggle to get hold of them.

4. One of the participants left Saskatoon for more than one month after I met him/her for the first time which slowed down the process of the work.

5. One of the participants passed away suddenly one or two days prior to my interview with her/him.

6. Finding a space for conducting interviews was a serious issue for some time which resulted in delaying the process of the work. Ultimately one of the key members of AIDS Saskatoon offered an isolated vacant place to be utilized for

this purpose.

3.7 Ethical Considerations

Ethics approval was gained from the University of Saskatchewan Review Ethics Board for behavioral research. As Punch (1998) argues, "a professional code of ethics is beneficial as a guideline that alerts researchers to the ethical dimensions of their work, particularly prior to entry". All the questions asked through the interviews were related to those in the interview protocol that was submitted for review.

All participants were provided with a letter of introduction and explanation of the research project (Appendix A), to ensure that they understood the objectives of the study before hand and to make sure their participation was voluntary (Silverman, 2001). A letter of consent to participate in the interview process was attached to the introduction letter, clearly outlining all rights and understandings (Appendix B). Participants were informed of their right to withdraw any or all of their responses at any time. A consent form for signature was given at the time of data collection. Simultaneously, a consent protocol was verbally presented prior to conducting the interview. Every participant signed the consent form indicating his/her consent to participate in the data collection process.

Because of the small size of the organization participants were recruited from, extra precautions were taken to ensure the confidentiality. This was possible through using pseudonyms, deleting all personal information from transcripts, and avoiding the use of names or other identifiable information while presenting a discussion of findings. Also, recordings of participants and transcripts were labeled with numeric codes and stored in a different location than consent forms and the pseudonym/coding reference.

Information such as addresses, phone numbers, and any other personal information were also stored in a locked location apart from the transcripts and recordings.

3.8 Limitations, Strengths and Recommendations

Research reliability requires that the researcher's methods and analysis be comprehensive, honest and accurate, and also that they properly address the research questions (Mason, 2002). Research validity also requires that researchers accurately measure or explain what he/she claims to be measuring or explaining (Mason, 2002). In order to accomplish this, researchers must go back over the directions of method and the process that he/she took to reach an interpretation.

In particular, this study involved 10 people who were from different groups and backgrounds in society. The study sample was diverse for the reason that each participant had experienced various circumstances at the time of diagnosis.

The sampling method used for this study was not random. Since I interviewed almost all the key member of AIDS Saskatoon and those that I was able to reach from the founders, for the participants who were HIV positive I depended on one of the staff members in selecting participants because it was not possible for me to figure out who was HIV positive or not. This sampling method was chosen because I wanted to interview people who could best answer the study's central questions.

Aside from these limitations, I believe that this research will provide useful information on how a health social movement reflects increasing doubts regarding the

importance of science in solving social problems and increasing doubts about how society should be organized and governed. This movement in general turns attention to things like the partnership between official and community based organizations, and the role of the expert versus the non-expert in complex, contemporary societies (Habermas, 1984)

Qualitative studies of movements such as this contribute in giving deeper understandings of the issues concerning new social movements (Kaltoft, 2001). This study's results suggest that health social movements such as AIDS Saskatoon are mainly lifeworld focused. The results also highlight the contribution of health social movements in rebuilding the public spheres.

What is most instructive about the results of this study is that new social movements like AIDS Saskatoon could have the potential to promote democratization and emancipation of the system, and thus contribute to correcting the one-sided rationalization of modernity. Further research might use different theoretical approaches such as Resource Mobilization theory to explore how AIDS Saskatoon manages to continue its work, recruit new members, utilize its recourses, and produce its own knowledge.

CHAPTER FOUR: FINDINGS

4.1. Introduction to the Findings of the Data

In order to obtain an understanding of what gave rise to AIDS Saskatoon as a health social movement (section 6.2), and to understand what kind of movement it is - offensive or defensive, and also to understand its functionality within the Canadian civil society, a total of 10 people were interviewed. Of these, two were among the founders of AIDS Saskatoon; three were from the current administration of AIDS Saskatoon; and five were HIV positive individuals who are affiliated with AIDS Saskatoon. The interviewing process started October 1st, 2007 and ended by March 17th, 2008. Due to the ethical considerations concerning participant s' anonymity participants are numbered sequentially.

The qualitative data presented in this chapter provide an in depth understanding of the process of the colonization of the lifeworld of people living with HIV/AIDS. The next chapter presents themes related to the role assumed by AIDS Saskatoon within the Canadian civil society. In the balance of this chapter I present themes that emerged from the interviews with the founders, administrative persons and the current members who are HIV positive. The purpose of this chapter is to provide an understanding of the lifeworld colonization patterns that can be linked to the rise of the AIDS Saskatoon as a health social movement.

4.2 AIDS Saskatoon's Formation Process

4.2.1 The Starting Point for the AIDS Saskatoon group

AIDS stands for Acquired Immunodeficiency Syndrome. In North America it emerged in the early 1980s as an epidemic, especially among homosexual men.

The origin of the HIV virus dates back to the year 1930, yet the first case of HIV was not found until 1981. The Canadian health record shows that in 1982 the first case of AIDS was diagnosed, while the first Canadian death attributed to AIDS occurred in 1983, and 21,000 people have since died (Health Canada, 2002). It is therefore not out of the ordinary to find that local responses to such phenomenon, like self help groups, health social movements, and nongovernmental organizations date back to that period.

According to Health Canada, HIV/AIDS first became visible in male homosexual populations and among those who contracted the disease through the blood supply. This threat was taken seriously by the male homosexual populations and, in response, they started to mobilize into small volunteer-based organizations in the early 1980s. Health Canada records show that AIDS Vancouver and the AIDS Committee of Toronto were the first community-based AIDS organizations to come to being in Canada around 1983 (Health Canada, 2002). AIDS Saskatoon is not an exception to this fact and, as one of the founders of AIDS Saskatoon stated, not very long after it became into being:

> The AIDS Saskatoon group formed in about the spring of 1986, officially, although we had been doing some work prior to then. (Participant number 1)

4.2.2 Legitimacy and Funding

The lack of response from the health system into the crises of HIV/AIDS, stigma, discrimination, and homosexual issues are the major themes that come up when participants talk of the formation of AIDS Saskatoon. Participant number 1 makes this clear in the following quotation:

> The main motivation for the men who initially started the group was the situation of this disease that was really infecting homosexual men and there didn't seem to be any response from the health system, and there didn't seem to be a lot of understanding about it, and there didn't seem to be a lot of information to help

individuals protect themselves (Participant number 1).

Participant number 2, who is one of the founders of AIDS Saskatoon, similarly stated that:

> People got together to form AIDS Saskatoon because HIV was becoming an issue – a priority – because people were testing positive in the city especially homosexual men and at that time, in the period from '81 to '86 as was everywhere there was a lot of misinformation, a lot of paranoia and confusion, so that was their response to deal with the situation (Participant number 2).

Participant number 1, points out the first challenges that faced the group in its early stages, explaining how they had to be registered as a nonprofit organization although they had existed before just as a group:

> It was about seven homosexual men, initially, who formed the initial board of AIDS Saskatoon, but we had to have some legitimacy, because as a group you need to be organized legally, you need to be recognized legally as a social being, in order to be able to deal with the system. And we also wanted to construct some ways of funding, and the possibility was there to get some funds federally or even provincially – so we became a non-profit corporation (Participant number 1).

4.2.3 The Founders of AIDS Saskatoon

The description of those who were involved in the founding of AIDS Saskatoon comes in accord with the literature of new social movements in which members of such movements are depicted as middle class people with a good level of living and education. However, and as explained in the subsections below, all participants pointed to a dramatic change to this fact when it comes to those affiliated with the movement saying that the majority of them are coming from marginalized groups. The following statements explain this fact:

> There were not street people among the founders. I was a manger at home care, I

was a united church minister, and a couple other people had fairly good jobs in computers. There was one person who wasn't really employed and had some mental health issues I believe he was on assistance. So I would say all of them were middle – middle to lower class (Participant number 1).

Predominantly, there was a lot of homosexual men involved very early on and you're talking about a mobilized group of people which for the most part tended to be – not in all cases, but for the most part – decent education, they were articulate, they knew what their agenda was and they knew how to push it to the front of the line, and get it noticed, and get stuff acted on (Participant number 2).

4.2.4 The Size of the Movement and its Members

According to participants the number of those who are involved with AIDS Saskatoon has been subject to change all through the movement's history moving up and down depending on time. To have an idea of the size of the movement in its earlier stages Participants number 1 and number 2 explained:

In the first year there were some other people involved not everyone had to be on the board. But it wasn't really big. There was about seven of us on the board and, you know, there might have been twice this number of other members (Participant number 1).

If you look at organizations and the people who got involved probably very early on in the 80s, and the people who got involved in the 90s – not in all cases, but many of them tended to be people who were positive (Participant number 2).

4.3 Colonization Process

4.3.1 Stigmatization and Discrimination

Participants at the administrative and member levels explain the challenges of dealing with two types of stigmatization and discrimination; the first type of stigmatization and discrimination comes from the community at large, and the second type comes from the health system itself and also from state organizations. The following comments give details on that.

People equated AIDS with being homosexual. So there was certainly a challenge through our process, while we were dealing with AIDS and its consequences trying to make it fairly broad-based, there was also underlying stigmatization and discrimination, and as an organization we really needed to deal with both issues (Participant number 1).

Participant number 3 stresses the same fact saying:

Back in the mid-90s, the majority of the people we worked with were homosexual men. Many of them had family issues, so those folks who were on their own some of them had good family support – but the majority of the men we worked with lived alone and didn't have contact with their original families, so there was a lot of issues around homophobia stigmatization and things like that.

He/she then takes the talk bit further and comments on the health care system saying:

There are still a lot of issues around even hospital and medical care. Although there are some good doctors and health care officials that are still around, there are other medical care and staff that were not always appropriate when it comes to dealing with those who are HIV positive especially outside of Saskatoon.

Participant number 10 talked about the role of preconceived ideas in perpetuating

discrimination and stigma:

Even with social work students, I mean – they go to school and they want to come out and change the world, but the reality is everybody comes in with preconceived notions about people that are not the same as them. And somehow they must have done something to deserve ending up where they are. And because we haven't experienced life the same we really don't know the circumstances and the background of each individual. So that is why particularly in AIDS Saskatoon we accept people exactly at face value; if you walk in, you have issues, we are here and we listen.

From a different angle Participant number 2 explained the consequences of going public

with the AIDS status:

When you become very vocal and/or visible, the immediate sense is that 'I'm okay with it' but down the road it has implications, if you want to carry on in a

different way in your life, it has implications for employment it has implications for partners, you know, all sorts of things.

And he/she adds some interesting points about how those that are less fortunate being discriminated against by the system:

I'm being discriminated against in the sense that the waiting lists are so long to see somebody. So once again, it's about supply and demand - the demand outstrips the supply so if you have money access is less of an issue. If you don't, then it is more of a challenge.

Participant number 7 explained the problems that he/she is facing because of his/her HIV status in the job field:

I have faced discrimination because of my HIV status in other ways, like job-wise, you know. I know for a fact that I can't work in health food industries, healthcare, 'cause if I get cut or something like that it would be a problem. I know for a fact I can't do that but if I look after myself and be real careful, I don't see why I can't wash dishes or something of such nature.

Participant number 6 spoke strongly to the problem of stigma that she/he experienced within his/her local community:

I think it was the year 1999 or 2000 that I went public with my HIV positive status with all my people I work with, neighbors, and close friends. Some of the reactions were good, but some of them were very bad. I have had my car torched, I've been called names, and people writing shit about me on the wall.

Participant number 8 explained how for the fear of stigma did not expose his/her HIV status for many years:

When I first got it, when I was first diagnosed people were kind of leery about it, it was like 'oh, freaking; oh, stay away from it' so I didn't tell my family until up to a few years ago because I was kind of scared about that.

4.3.2 Doctor Patient Relationship 'intimidation and lack of trust'

One of the eminent issues that most participants talked strongly to was the lack of trust in the medical system from those living with HIV and AIDS especially that related to marginalized groups. The majority of participants visit their doctors less than they should and some do not abide by their doctors' instructions. Such a situation could tell us a lot about the colonization process when people feel that they are not listened to, which means the voice of medicine is taking over the voice of the lifeworld and the result is loss of communication and the lack of trust. The following statements describe in depth such conditions.

Participant number 3, a staff member, gave from her/his day-to-day experience a detailed description of this recurring situation:

> A lot of the people that we see nowadays are quite intimidated by the health care system. Part of that is a lot of them are people who use injection drugs, and they know full well that many people look down on them because of that, and many of them feel often that they're not listened to in the health care system, that they're dismissed as just a junkie. And they use that phrase themselves. They say 'well, they think I'm just a junkie'. So, often, we have many of them that don't even access the health care system because they've had such difficulties with it. But I have accompanied people to go visit their doctor, to be with them while they're talking to their doctor.

And he/she also adds:

> Because they don't feel listened to, they don't feel that anyone hears them. I think sometimes they don't think they're taken seriously because they're 'just a junkie', in quotes. There is a great deal of discrimination and judgment around people who use street drugs, or people who have been street involved in any way, and they're well aware of that.

Participant number 4, who is also a staff member, pointed to the same condition saying:

HIV is hitting people who are also already otherwise disadvantaged - so it is hitting people who use drugs, people who don't have stable income, and who are on social assistance, so AIDS Saskatoon isn't really just about addressing HIV in our community. A lot of the work we do is about addressing some of other factors such as housing issues, security, and food safety issues, all these kinds of things which really effect people's health in general.

Participant number 1, who is one of the founders of AIDS Saskatoon, spoke to the lack of trust in the early stages of the movement.

And part of our reason for being, as we explained it, is because a lot of especially homosexual men and people with AIDS did not trust the mainstream medical system. So we were always very cautious. We even thought there could be some unconscious discrimination.

Participant number 5 explains:

The thing is that you need access to health care and you need to see a doctor and have some treatment. But if you don't trust the health care system's settings, if you don't trust that method of addressing health issues, you're not going to go to the doctor.

Participant number 7 and number 8, who are members of AIDS Saskatoon and also HIV positive, spoke to the lack of trust issue and had to say the following:

I don't trust my doctor. I can't really. It takes me a long time to trust him, patient wise I would go to him, but I wouldn't trust him to the point where, 'oh you got to take this, and you got to do this' – not to the point to give my freaking life over to him? That is for sure. I trust him to a certain point but after that, no.

Participant number 8 states:

My doctor is quitting so I'm going to be really wary to meet the next doctor, and I wonder whether I can trust him or not. I don't know about the next doctor that I'm going to meet. Some of me wants to go traditionally where I don't see a doctor for the rest of my life, but some of me doesn't want to go that way.

Both Participants declared that they do not abide by their physicians' instructions providing some explanation that points out two facts: first, the power challenge between the voice of medicine (doctors) and the voice of lifeworld (patients); and second, the lack of communicative actions which result in suppressing the voice of the lifeworld and creating misunderstandings.

Participant number 7:

> I do not abide with my doctor's instructions because for example he wants to start me on the medication right now but I don't want to really start it. My lifestyle is kind of chaotic right now, so if I started the medication right now like he wanted me to, I would have to do it regularly at a certain time on a certain day and not miss it, because if I miss it the virus tends to mutate, and then the medication doesn't work. So I got to be ready to take the responsibility, I guess, to take my meds at a certain time – but I don't want to, 'cause of my lifestyle is kind of all over the place, so I know I would miss it. The virus tends to mutate around the medication, so then I'd have to get different meds it just keeps on and on, so once I get settled and organized, I'll probably get on the meds but right now, no.

Participant number 8:

> I do not abide with my doctor's instruction, one of the reasons is that the first time they put me on medication I had allergic reaction and that kind of scared me to take it again so I stopped taking it. And then I would ask him for my counts numbers, if they were good I don't take medication even though he wants me to take it.

The following quote from the Participant number 4 is in total accord with communicative action theory's stand concerning instrumental rationality and how it renders people to mere clients or consumers.

> I think that in a lot of places in our community when people walk in they feel like they're not listened to, and they feel like they're not valued as a person they're either seen as a medical client or as a consumer of a service of this organization, that kind of thing.

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4.3.3 People living with AIDS and Marginalization

Marginalization is relevant to the process of the colonization of the life-world in a sense that in such condition of the welfare state in which the instrumental rationality is taking over the life-world, those who have more of "money, votes and power" come before those who do not and who are not listened to. Participant number 10 makes this clear:

> If you are Aboriginal, if you are a woman – an Aboriginal woman; if you are Aboriginal and a sex-trade worker, then there's a whole lot of stuff. How can I go in somewhere and talk to somebody, and say I need access to a social worker because I want to talk about, you know, making changes in my life because I may have been exposed to HIV – but I really can't cope with it right now. I don't really want to talk about it, but I just want to know some information. You wouldn't get that, because society in general looks at you and says well you are really not desirable – you must have made some really bad choices along the way that you are where you are today, so you know what? Just deal with it. And that is the way that people's attitudes are – we could pretend that they are not, but they are.

And in the words of Participant number 4:

> Twenty years ago the demographic was it is homosexual men who have HIV, and now the demographic is, especially here in Saskatoon, is Aboriginal people, people with low income, people who use injection drugs, and women, kind of thing. That is where the most of the infections are happening, and those populations are populations who have traditionally just been pushed aside and ignored in our community.

Participant number 2 underlined how marginalized groups would rotate in the same circle because they do not have equal opportunity with others:

> Marginalized groups of people with low education or no education – have a lot harder time to make choices because they don't have the means and they do not even know about what is available for them. We had a forum of positive people talking and, basically, I said even if we came up with a vaccine today that would

eliminate the threat of HIV or AIDS, a lot of the people who are entering or accessing organizations– they would just move on to another disease. I said it's a crutch for some people because of their lack of resources that they have.

Participant number 1 described one kind of marginalization AIDS Saskatoon faced in its earlier stages:

And we faced marginalization and discrimination in our first steps as an organization, for example we were refused to rent a space when we first started looking for one. So, certainly some people did see us as this group to avoid. Besides that, we were hearing stories from individuals who stated that health care providers were not understanding, not sensitive, and quite uncomfortable with them.

4.3.4 Affording Prescriptions

All Participants who are medicated emphasized a frustration with the rising costs of their prescription as this Participant number 6 elaborates:

If a person has one prescription that's six hundred and fifty dollars a month, how is a person supposed to work and pay for his/her prescription?

Participant number 8 underlined the same issue:

One of the things that I couldn't afford to get is the ankle brace, and I just got surgery today and the doctor's asking me to get an orthopedic cast put on it, which costs up to two hundred dollars and I can not afford that and they're not going to cover it.

Participant number 7 pointed out difficulties getting supplementary medication saying:

Supplements and the vitamins are really expensive, and I can't do it. I can maybe afford my multi-vitamins, but I'm supposed to be taking vitamin Bs too, and Vitamin Cs, the Calcium's and the Irons. I can't afford all those. I used to get those Lakota pills but they are not covered too. Those vitamins were really expensive and I couldn't buy them and I needed them.

Just as with the above testimonies Participant number 10 stated that:

> It was an issue in the sense of not being fully aware of that prior to the selection, because the doctor wanted to try these particular drugs and, then, found out that one wasn't covered. And, in that situation, I think one prescription was eight hundred and some dollars a month, which I couldn't afford at all.

4.3.5 Access to Health Insurance

Accessing health insurance and prescription costs are some indicators of finding out about how the economic system is invading the lifeworld and turning citizens into clients of the welfare state. And also they are one of the important factors that push people to get together and mobilize. Most study participants stated that they do not apply for insurance because they know that they are not insurable. Two of the Participants (numbers 6 and 10) made this clear:

> I've got all kinds of problems with this issue, because I work for a company that offers health benefits, but I can't get access to the health benefits because, if they found out I was HIV positive, I would be fired. So you figure that one out (Participant number 6).

> I've always asked this question a number of times. There's always stuff that comes in the mail and they're trying to sell you life insurance, etcetera, and my response is always, well, I'm not insurable. And some of them they would respond is 'yes, you're insurable', but the real issue is will I be able to collect on any of the benefits, and the answer is always no. So really, is it in my interest to buy any of that stuff? (Participant number 10).

4.4 AIDS Saskatoon's Mobilization Activities

4.4.1 Ways to Pressure the System

One of the essential features of the social movements is the ability to mobilize for the sake of restoring or bringing about some changes to society. The following comments show how AIDS Saskatoon worked towards restoring the lifeworld for its members. As

well as dealing with various social issues, raising awareness about discrimination,

making positions on the whole anonymous versus confidential HIV testing, and also

taking positions on the notion that hospital staff should know about all the issues

surrounding people who have AIDS.

Participant number 2:

> There was a big concern once about someone who was infected and was in the hospital going into surgery, and this doctor informed the hospital – and you can understand why. He was worried that people wouldn't know – and our position was that you should be taking universal precautions, regardless. You do not know whether he has AIDS or not, so you should be wearing gloves when you are dealing with people especially if you are taking blood or those sorts of things.

Participant number 1:

> AIDS Saskatoon helped to mobilize Public Health in Saskatoon. The provincial government was very reticent to do anything in this regard, and through our advocacy and mobilization we actually caused them to respond. We moved both Public Health and the provincial government to respond to the AIDS related issues.

Participant number 4:

> At some point the executive director at AIDS Saskatoon, the executive director at Homosexual and Lesbian Health Services, the executive director at Aids Regina, they were making appointments with their local MLA's, they were making appointments with Ministers and part of it was at that time, the Saskatchewan Aids Network – which was a coalition of the groups – was coming together and speaking as a voice for the priorities of education, service delivery, and funding.

Participant number 2:

> We kept meeting with those were in charge like local MLA's, and Ministers and making appointments, and saying to them that 'okay, it says this in your policy – you are not doing this. You say this but you are doing this. Things do not match up. So we started challenging them on their own policy and saying 'this is not

good enough, this is not adequate, and that is how we managed to get a lot of work done.

4.4.2 Anonymous Testing Versus Confidential Testing

There are two modes of HIV testing: confidential test in which names of patients are recorded, and anonymous test in which the names of patients are not recorded. The position of health care officials is that anonymous testing should be ceased and replaced by confidential testing to improve reporting data accuracy. AIDS activists take a different position on this matter arguing that the cessation of anonymous testing would discourage people who are at risk of contracting the virus from undergoing testing. Participant number 1 explains the position of AIDS Saskatoon in the following:

> In the '80s because of the severe stigma, and potential discrimination, we thought that by having it reportable it would discourage people from being tested while they must know for their own care and others. We didn't totally buy the argument that counseling could still be provided. People could be given an identifier, come back, get counseling, and you wouldn't necessarily have to know the identity of that person. And actually there were anonymous testing sites set up in some cities like Toronto and such.

4.4.3 Lobbying Work

According to Participants' testimonies there was a lot of lobbying on many levels - lobbying was done to get more rights for the people with AIDS, like drug coverage, delivering services better for people that are positive, and also changing how the curriculum was being handled concerning AIDS. The following comments make this clear:

Participant number 2:

> At that point there were a lot of drugs just coming on available, being approved by Health Canada. But they were not covered under the drug plan in this province. The province was lobbied to add those to that for coverage. You have people that

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are positive and they are not on social services, it was the whole issue of getting drug coverage, expanding exceptional drug coverage status so that if you were working and you could not afford coverage and you needed the drugs, your coverage is based on what your income is.

Participant number 10:

> In 1993, we did the Positive Peoples forum and the report with service delivery came out in 1994, we went back to the service delivery people and talked about how to deliver services better for people that are positive, because the demand is different; the different groups of people we were serving. And we made our stand clear that the challenges were with people not understanding some of the different requirements for women, lesbians and homosexual men.

Participant number 2:

> Kind of such lobbying was happening when we needed to change how the curriculum was being handled, and how it was taught which was done in conjunction with Aids Regina. There was a lot of work done to bring that about and it did occur even though there was big resistance to it.

4.4.4 Picketing, Letter Writing, and Faxing

One of the very intriguing ways of challenging the system to get their attentions

and bring them in to the table that was done at some point by AIDS Saskatoon was the

fax campaign. Participant number 2 described this campaign:

> One of the campaigns that was organized to bring the Ministry of Health to the table was when a petition that was signed by many people, and was being faxed from Aids Saskatoon non stop to the minister's office. Eventfully they called and asked for us to quit faxing because no one else could fax any correspondence into the department that day. They were bogged down with our five hundred page fax. So we got their attention and got the opportunity to meet with them and talk about the things that need to be changed.

And he/she also went on to describe another event in which members of AIDS Saskatoon

undertook some picketing activities to draw the public attention to AIDS issues and ask

for funding:

> There was even some picketing that was going on downtown Saskatoon when the NDP party had their convention. So we talked about the lack of funding and we did up t-shirts with the giant band-aid, we protested their band-aid solution of dealing with HIV and AIDS. And our message was we need more than a band-aid solution. We need action on many issues.

4.4.5 Using the Media

Founders of AIDS Saskatoon indicated that they were a bit concerned about their credibility as an organization, so they worked hard to educate themselves and made big efforts to learn as much as they could about AIDS so they could speak with credibility. And they said that they managed to use the media quite well for that purpose. The following statements make this clear:

Participant number 1:

> Like I said, we formed this group kind of informally and it kind of became legitimate quite quickly. And because there wasn't really much of a voice for people with AIDS the media took quick interest in our movement and this was helpful in gaining some credibility.

Participant number 2:

> The media took real interest in the group - a bit surprisingly actually. As soon as this group was formed and started getting the word out the media started phoning for 'what should have happened', for the other side of the story kind of things.

4.4.6 AIDS Saskatoon's Approach Concerning Health

The focus of AIDS Saskatoon as indicated by the participants initially was very much homosexual men who were infected and then IV drug use, people infected through blood transfusion, and women passing on the virus through pregnancy became much more of a concern. So they started dealing more and more with those much broader

issues. While dealing with such various issues, members of AIDS Saskatoon were adopting a special approach that is different from the official one, as the following comments by some Participants explain:

> There's still, I think, quite an undercurrent of fear and a lack of understanding and, to some degree, hatred. My sense is that there's still a need for those types of groups. Like I say, I think the group evolved to be a little bit more broader-based, and a little more mainstream (Participant number 1).

Participant number 2:

> Health is not simply how much access I have to medication or how much access I have to my family doctor or my specialist or my dentist. Health has to do with the broader thing like your social context, and how do you feel about yourself whether you are happy or not. Also the social constructs whether you have a family or you do not have one and whether you have a social support network or not. Those things are just as important because we know stress is relative to a healthy immune system as well as diet, as well as exercise and these are the things that are ignored by the health system while are being at the core of AIDS Saskatoon's interest.

Participant number 10:

> Dealing with people that are infected could mean lots of issues, whether it is their family, their friends, or the health care system, there is a whole gamut of issues involved so it is an important thing to look at AIDS Saskatoon as sort of a social health movement. This movement brought a lot of people together in extraordinary ways, they worked together to get their stuff done and they succeeded in achieving a lot of work.

Participant number 1:

> We borrowed from other organizations, like Aids Vancouver a lot. We did have contact with the local public health group too, there was a physician in the community who had some interest, and we as a group got advice from professionals and other organizations.

> We also thought we were in a better position to provide frank information; which,

sometimes government is much more restricted. We thought that some people would feel much more comfortable dealing with a grassroots organization that they knew was made up of people on the ground.

AIDS Saskatoon in big part of it is a peer support type organization, where there would be a social network for support, and also assisting in many other ways. They weren't providing the hard medical care; doctors and nurses were providing that. Thus they saw themselves as advocacy and peer support movement.

As a group when we got together our priorities, were advocate and support those are infected, educate those that are at risk so they would not contract the virus and, as well as education of the general public, and care providers. We also developed program of funding, so if some people needed some financial assistance we could help out.

Participant number 2:

I think there is a recognition that says a community-based organization is better able to reach marginal groups, and I think it has a greater trust than mainstream groups. So I think that is one the reasons why AIDS Saskatoon continued to exist.

4.5 Summary

This chapter is divided into four subsections starting with outlining the formation process of Aids Saskatoon. The first part dealt with the manifestation of lifeworld colonization in which respondents spoke of frustration over the deficient response from the health care system to the AIDS crisis. And most of the problems of which they spoke were sociological in nature. For example, they spoke at length about discrimination and stigmatization against people with AIDS caused by the misunderstanding associated with the lack of education of the individuals in the community, and also health care workers in regard to AIDS issues. In particular, they pointed out the notion that seemed to be widely spread in which people with AIDS are to be blamed for their condition because somehow

they must have done something to deserve ending up where they are.

The second part of this analysis revealed that marginalization is prevalent and the main concern regarding the doctor patient relationship. This section also gave clear indication that the language of power and money is taking over communicatively rational communications.

The third part of this chapter dealt with respondents' views of solutions to some of the issues surrounding AIDS. By saying 'no' to the dominant model of relations through the mobilization activities, foe example, they revealed to me much self-esteem and their words and actions were palpably self-affirming.

Quotations in the fourth part revealed a broad sense of purpose among respondents indicating their approach to the health issues.

As the study proceeded, however, it became clearer to me that what respondents wanted to convey through their words was that the need for AIDS Saskatoon is growing and the fact that it is still around means a lot for its member and the community in general.

CHAPTER FIVE: AIDS SASKATOON'S ROLE

The qualitative data presented in this chapter provide an in depth understanding of the functions that social movements like AIDS Saskatoon assume within Canadian civil society. This chapter focuses on the effects health social movements bring about within Canadian society, and as it is stated above, under this inquiry comes the question of what role AIDS Saskatoon may have as a force of change, democratization, emancipation and hence whether AIDS Saskatoon can best best be understood as an offensive or defensive social movement.

5.1 Forming Discourses

5.1.1 Creating Autonomous Spaces, Extending the Public Sphere

All participants in this study stressed the importance of having a space within AIDS Saskatoon where people could meet and discuss their issues, have a voice, get a chance to be heard, learn from each other's experiences and build collective identity. Participant number 3 points out that AIDS Saskatoon is the only place where people can get together to talk about what matters to them:

> Aside from getting medical care, there isn't really any other place for people to turn to where you can socialize with out being identified with your HIV status, and where you could say your opinion about what matters to you and be sure that you are being heard.

This comment illustrates that being in such an atmosphere for someone with HIV/AIDS serves two purposes. The first is to release them from the burden of being identified with the sickness. Most participants consider this release as empowering in itself. The second is to enable the voicing of one's opinion in such a setting where everybody has the right

to talk and to be heard and to come to a common understanding. Another participant

elaborated on that sentiment to explain how people utilize in many ways the space AIDS

Saskatoon offers for them:

> I think one of the neat things about what we do is that we provide a space for people where they would feel comfortable, safe, and wanted. And also spaces where they can meet, build relationships, discuss their issues and learn things in their own way, which is not something that I think they do get in a regular medical clinical setting (Participant number 4).

The potential of this space and the meetings that take place in it are not limited to

expressing one's feelings and stands about certain issues but rather as a learning

opportunity and a healing process for all participants. Participant number 10 made that

clear in this way:

> At some point activities started to organize where people got together and have discussions – it was an opportunity for positive people to come together and meet as a group. It was a learning curve for everybody and a healing process in some ways.

The following statement by Participant number 2 explains more the learning aspect of

being involved in AIDS Saskatoon's activates:

> Being involved with AIDS Saskatoon, I found it in many ways, an opportunity to put a lot of my practical skills together.

And Participant number 8 gave the following testimony describing how getting together

and participating in meetings and discussions activities can be a kind of healing process

for those living with AIDS:

> What I noticed is when my friends are getting sick because of the complication of the virus, it gets them angry. They start getting angry about it because they know it is finally affecting their bodies. But the few conversations we have together it

makes them calm down.

5.1.2 Grassroots Approaches

Participants expressed the importance of having grassroots approaches like the one AIDS Saskatoon is taking because people feel more comfortable dealing with it. Participant number 1 signified this sentiment in the following statement:

> People feel much more comfortable discussing their issues, and dealing with grassroots organization that they knew was made up of people on the ground.

Participant number 3 explained the difference between the role that AIDS Saskatoon is assuming in the community and the one of official medicine:

> There needs to be a grassroots voice, a doctor has his particular frame of reference and his particular expertise. Our particular frame of reference and our particular expertise is different, what is important for us is that all the voices get heard in whatever policy is being set.

5.1.3 Promoting Participatory Communication

Participants indicated that having both women's and men's groups that were mostly regarded as successful throughout Aids Saskatoon's history. In group meetings, as all participants explained, people with HIV get together, talk about the sickness and its complications socially, economically, and health wise. The following comments make this clear:

> We have gone along in the past twelve years. The Men's group, for example, was one of our successes. They meet to discuss different issues, they share their personal lives with one another, learn from each other's experience, and in that way they support and empower each other (Participant number 5).

> I participated in a group discussion regarding AIDS lots of different times. We formed a group discussion here in AIDS Saskatoon, we had a men's group with people that are HIV positive that would come together and talk about their issues and conditions. It helped me lots, because if you can't get it right in your head,

how are you going to be able to survive? (Participant number 6)

There was a women's book club that was organized, which was a chance for them to meet and exchange books, and once in a while in each book that went out would be a bookplate that said we will be having a meeting on this date at this space, there will be food, child care, a chance to meet and talk about the book or some other topics and connect as people (Participant number 4).

Participants 8 and 7 gave a clearer idea about what was going on those meetings in terms of the most discussed topics and also how they were organized:

People talk about symptoms, what exactly gets them sick, the different kinds of treatments and what is new in that regard (Participant number 8).

I have participated in many group discussions and in some occasions I was involved in presenting to a group about AIDS and its related issues. So I would be the main speaker and then there would be an open discussion so everybody will be involved (Participant number 8).

Here at AIDS Saskatoon I have participated in group discussion many times. Usually when we get together, its about how everybody is doing in all levels, socially and health wise, how is this treatment going, and what is new in regarding to the virus. I have met lots of people that go through there and I was able to learn a lot from them (Participant number 7).

5.2 Empowerment and Emancipation

5.2.1 Empowering People, Collective Identity and Shared Experiences

The concept of empowering is manifested in various stages and different activates practiced by AIDS Saskatoon. The previous section showed how getting a voice, being heard, and learning to be at peace with the sickness is empowering. In this section, different forms of the empowerment including facing the stigma, fighting back, getting a job, having a supporting social network, having advocacy, learning from each other's

experiences and learning to help oneself and others are described. The following comment by Participant number 10 explains the position AIDS Saskatoon takes in counteracting some polices and procedures adopted by the health care system that could be disempowering to people living with AIDS:

> If somebody with HIV comes in to you and you say "what you need to do is go down to social services and get on social assistance - you can get this and this covered and, you do not need to work", you inadvertently disempowered him.

What comes to be obvious here is that, the over all objective for AIDS Saskatoon is to empower people and help them to take their matters on their own hands. The same participant goes further to illustrate this point:

> Lots of people are not able to stand up for themselves. Whether it is with their doctor, their spouse, or the health care system in all sorts of ways being involved with such a network it makes you stronger and, if you were weak before, it will push you up and make you decide to fight back.

> I think that people need to have value and they need to go to work as much as they are able to. You need to be able to take care of yourself, but you do need the resources of knowing what is available out there. What are my choices? Do I have to go on therapy? Do I not have to go on therapy? What's involved with making that decision? Who do I trust? Who do I not trust? Well, those were all learning things for us back then (Participant number 2).

5.2.2 Social Network for Support and Advocacy

The overwhelming impression one gains from most participants when talking about advocacy and social network support is that AIDS Saskatoon was the natural alternative for filling a gap left open by the family and the health care system. Especially for those who have no families. They all talked strongly to these particular needs that ought to be met first in order for them to be able to fight the disease and its pertaining issues. The following comments make this clear:

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Besides food and shelter people have other basic requirements. They need social and moral support, love and a sense of belonging. If you cannot get that need met within your family unit, you need to get it somewhere else in order to move beyond that (Participant number 2).

I come here for the companionship for the good people that I know I can talk to them and they are not going to judge what I said. I just feel a lot better when I have talked about it with someone that cares and shares the same thoughts (Participant number 9).

People that have HIV and I know that they need help I refer them over here. Because without places like this to come to, you are just out there struggling on your own. I know for a fact that the struggle would be harder. When you are here you get the power to face the fact that you might be in denial, or might have just blown it off, and also to know whether the lifestyle that you are leading is making you sicker (Participant number 6).

For me having been through homosexual groups, I saw a real need for this kind of work, and real need for such community groups to advocate for human rights legislation, so I felt very comfortable in that milieu (Participant number 1).

5.2.3 Knowledge Transmission, Learning from Each Other's Experiences

Another form of empowerment is getting rid of some burdens through learning from other people's experiences such as coping with challenges, overcoming the fear of stigma, and defeating negative emotions that accompany the sickness. The following comments explain this in some details:

By getting together here and sharing our experience with one another we get some empowerment. When someone would be saying I have this challenge in my life, and this is how I dealt with it, it gives someone else a sense that he himself can do it (Participant number 2).

I am more aware of how I act with life than I was before. Back then I would be like "yeah, I have HIV and I have HEP C, so I am going to die. So what?" Before I was involved with AIDS Saskatoon I use to have kind of fatalistic attitude, just go out there and party that is what I would do. But now I am more in tune with it,

so I am more out there to help people and care for myself and others (Participant number 7).

I learned to be open about my health issues and share my thoughts and experience because that is how you get the power back in you hands and start to be in peace with it. At first I was very reserved and didn't want to talk about it to anybody but that did not help at all. By listening to other people's stories and by hearing about their experiences you learn a lot (Participant number 8).

One of the things that I learned through the meetings is the methadone – it's a synthetic drug – and when you take it, it doesn't affect your HIV, or your liver, because it's a synthetic drug. It is saving a lot of people's life while a lot of them do not know about it. (Participant number 8)

Being in AIDS Saskatoon It was a healing process for me. It was quite emotional to find out that T was sick, and it took a toll on me. It wasn't easy. It was a difficult time to see how the disease had taken effect on him/her as a person as a whole, and to see her/him dying. Being involved with AIDS Saskatoon is a growing opportunity to heal and a chance to carry on T's spirit (Participant number 5).

Everybody's experiences are a little bit different, we don't live the same lifestyle, so when we get together we talk about the way everybody lives with the sickness, our different conditions, and medications and how it affects everything (Participant number 6).

Lately I ran into a girl that was just newly diagnosed she was devastated and thought it was a death sentence. She was thinking that she will be dying in a matter of a year or so. I explained to her that I had been positive for many years and I was not even on medication, and if you look after yourself and you quit doing harmful things to your body you could live long and normal life. So after being with us she started be her normal self again (Participant number 9).

The above quotes very clearly distinguish the social warmth that cannot be gained

through the health system, but rather in such space as AIDS Saskatoon, where the media

of communication is not being affected by money and power. In which the person with

AIDS is not just a client but a complete rational human being, who could be engaged in

the process of deciding what matters to him or her. Participants number 3 and 4 signified

how empowering it can be for those with HIV to be treated as persons and not identified

solely by their sickness:

> That is always the hope. It is that wonderful word empowerment, when people just gain enough self confidence and enough ability to feel that they can deal with their issues themselves (Participant number 3).

> People here feel that they are listened to and valued as a person first. We are not about "well this is client so-and-so with HIV, whose major problems are this and that", it's just that human level what makes people choose to be here (Participant number 4).

> When people who come in here say that I come here because I am treated like a person first it is an indicative of some of what we do and more than that it is a way of empowering them (Participant number 4).

5.2.4 AIDS Saskatoon Source of Education

In addition to learning from each other's experiences, there is also the educational

role that AIDS Saskatoon carries out for its members and for the community at large.

Participants have indicated being educated through the information sessions and

pamphlets and other educational materials that AIDS Saskatoon makes available for

them. Participants number 10 and number 3 put it in this way:

> My sources of information have come through pretty much the organizations. The information out there is accessible to anyone, however, community based AIDS organizations provide probably the most comprehensive and accessible information (Participant number 10).

> There has always been kind of the two faces of AIDS Saskatoon, the education and prevention, which is more out in the community and trying to have an impact in the community, and then there has been the support side, which is working with the people who actually are HIV positive, or with their families members of friends and people like that (Participant number 3).

> While you interacting with the group here you keep learning, some people have to

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learn a whole new way to live in order to survive. The meds and the doctors are part of it, but that is just one part of it. So if you are running a picture or a puzzle without all the pieces, then you are incomplete. You need to put all the pieces together to be able to make it work, and in order for you to be able to do that you need to be engaged in a group (Participant number 6).

What I do know about the disease is stuff I've learned from AIDS Saskatoon. If it was not for AIDS Saskatoon I think I would still be a drug addict out on the street, being here has pushed me in a lot of different directions. Like going to rehab, and to be a better person – it is more important it helped me to have the will to be a better person (Participant number 9).

5.3 Appropriating Social Roles

5.3.1 AIDS Saskatoon as Starting Point

Participants indicated that AIDS Saskatoon serves in some aspects as an entry point for some people into the system, especially for those who probably would not be able to get into it themselves. Therefore AIDS Saskatoon's work is more about the ability to give people resources and also helping them getting access to resources. The following statements describe this:

It is a starting point, an entry point into the system, without it you would have people that may not ever get any help (Participant number 2).

If somebody is on social assistance, and they are finding it hard working with their social worker or there is some issues or they don't feel like they are being heard, they can call in - they have to sign forms to allow us to talk to the social worker–we do help sort out some of those problems for them, just where they need somebody on their side (Participant number 3).

Health wise they will point me in the right direction and make you aware of what resources that are available for you (Participant number 9).

AIDS Saskatoon's staff members have indicated that a big proportion of the people that

come through the doors of AIDS Saskatoon are from the aboriginal community, people

who don't have stable income or are on social assistance, who use injection drugs, and

people who have been involved in the street life one way or another. As Participant

number 4 put it, these segments of the population are the ones that have traditionally been

pushed aside and ignored in our community. And AIDS Saskatoon, through its members,

is taking on the challenge to work for those people and also to work with them.

Participants number 4 and number 5 explain this in some details:

> We are working right now with a 'students association' through the law college,
> on coming up with a resource to hand out to AIDS Saskatoon's people that in
> plain language spells out their rights as tenants, where to turn if they are having
> difficulties with their landlord, and what their options are. Because people who
> come through our door, it is not just that their rent gets jacked up, its also that
> their landlord bullies them, or treats them in a way that is legally not
> acceptable (Participant number 4).

> Yes, medical services and doctors' offices provide support to people who have
> HIV, but the reality is this aspect comes as the third highest concern in their lives
> right now, what comes before that is a place to live, food, and a sense of
> community, once those needs are met, then they can move on to addressing HIV
> (Participant number 4).

> Within those live with AIDS there are a lot of homelessness, poverty, and
> addictions. And to make this reality changes you have to have the federal and
> provincial governments involved in this process, and because it is hard to work to
> have them involved, I will be honest and say that is why AIDS Saskatoon is
> needed (Participant number 5).

5.3.2 Peer Support

Participants stressed the fact that there is always a role for community-based

organizations, even though they are not providing the medical care, the doctors and

nurses still providing that. Community-based organizations such as AIDS Saskatoon are

much more of a peer support and advocacy organization. And when participants talk

about providing peer support for each other a lot of it has to do with simple things yet

they might have a big impact for people with HIV. The peer support takes various forms

ranging from offering social network support, to having somebody that could be there

with a person as they were journeying with their illness, arranging to have somebody to

get groceries for them, accompanying them to medical appointments. The following

comments make this clear:

> With so many people dying, we had a well-trained group of volunteers called –
> I'm not going to remember – Care Team. And we had about thirty-five really well
> trained volunteers. We trained them really, really well based on a manual that
> Casey House Hospice in Toronto had developed. So those volunteers would go in
> and watch TV with somebody, or make supper for somebody, or just be with them
> overnight so they had somebody in the home with them (Participant number 3).

> We provide a space for people who don't have phones so they can phone to book
> their appointments with their doctors and their doctor's office might call back and
> leave messages for them here. We try to address some of those more basic
> concerns, like how can we connect you with resources in our community around
> (Participant number 4).

> We had Red Ribbon day – that's in September – and we raise funds for our
> emergency assistance plan, and that provides funding for some of people that go
> through special circumstances (Participant number 5).

5.3.3 Reconstruct Personality for Newly diagnosed People

Every participant stated that AIDS Saskatoon helped those who were newly

diagnosed with HIV to make healthier lifestyle choices, and to build up their self-

confidence and their self-esteem. AIDS Saskatoon also helped them learn how to live

peacefully with their disease, and how to help themselves and others. Tthese participants

elaborate in the following statements:

> When you find out you are diagnosed, your world crumbles and if you don't
> know how to put it back together, this is the place where you can come and talk to

somebody, and that is where they help you put it back together (Participant number 6).

In 1997 when I first diagnosed, I was totally lost and did not know what to do or where to go, in AIDS Saskatoon I found the persons that I could trust and tell that I was HIV positive. That was so supportive and helpful to me that is why I have just kept coming back (Participant number 9).

I was involved because I could contribute something to other people that I think felt the same, because when they basically got a diagnosis they had no life. And they would be thinking what else were they going to do with their time? It was an opportunity and it was a social network for some people because they didn't really have a lot of a life or a social network prior to that (Participant number 2).

Being here it gives you the pleasure to help another person that doesn't really know how to deal with it when they first get diagnosed. And also helping them in knowing this place, what resources are available for them, and what programs they got (Participant number 7).

I met a few girls who just came up to me and told me I just tested HIV positive, and I've directed them here. I am glad I did that because they were just young girls, eighteen year olds and they were lost and not sure what to do with their lives at that time. So they got all the help they needed and knew how to live with the sickness (Participant number 8).

I have more trust in sharing my thoughts and concerns with people from AIDS Saskatoon than my doctor. There are certain needs that cannot be met at your doctors' office and you find them here with your help group (Participant number 9).

5.4 Redefining Cultural Norms

5.4.1 Changing Mainstream Thinking

The work AIDS Saskatoon does, according to participants, is not just about HIV and the virus. It is about working to change culture so that people deal with diseases such as HIV not as a disease that exists in isolation but rather as one that has multiple social, psychological, economic, and medical aspects. As part of the struggle for cultural change,

AIDS Saskatoon also works to reduce negative attitudes and stigmatization towards those living with HIV and AIDS. The following describe some of the efforts that have been made by AIDS Saskatoon in this regard throughout its history:

> Over the years AIDS Saskatoon has been very active in supporting people with HIV accessing services and has provided education to the Department of Social Services so that they are aware of all the difficulties that people living with HIV experience in their lives (Participant number 4).

> We dealt with a lot of social issues, and certainly raised awareness about discrimination and made positions on the whole anonymous versus confidential, made positions on should hospital staff know about people who have AIDS (Participant number 1).

> From 1994 'til now we have far more community support, we have many more churches and church groups that are involved with us, we have many more individuals who are very supportive of us. We have more partnerships with other agencies than we used to have, so I think we've done a good job in those things. I can certainly see differences in that (Participant number 3).

> We have done a good job in educating people that HIV isn't about you are homosexual, you have AIDS but rather HIV should be everyone's concern because anyone who is sexually active, and engages in any kind of risky activities is at risk of contracting HIV (Participant number 4).

> AIDS Saskatoon has been very good at developing that model of dealing with people where they're at, and being a non-judgmental environment, and being open to everybody regardless to their orientations or choices (Participant number 10).

> We are not some large organization but we are a little bit more rooted or grounded in our community to the point where we aren't just responding to one thing. We are growing in many ways. We are experts on how to work with community, and individuals. We have expertise in how to share information, and how to partner with other organizations to affect change in our community (Participant number 4).

5.4.2 Winning Battles within the System

The founders of AIDS Saskatoon, as well as the staff members who participated

in this study, indicated that the provincial government at various points was very reticent to do anything in regard to the issues surrounding HIV. Thus, AIDS Saskatoon had to take the initiative and mobilize in order to bring about some changes and also to cause the provincial government to provide some response. In the following quotation from Participant number 3 describes the results of some mobilization activities of AIDS Saskatoon throughout its history:

> One of the things that we won a victory in some years ago was with the Department of Community Resources when we managed to get a designated case worker for people who were HIV positive, which meant this case worker would become well educated about HIV and AIDS, and all the issues people living with AIDS face, in order to deal with them more appropriately.

> We used to battle with Social Services a lot. We battled with them over various things and managed, for instance, to get a warm clothing allowance in the wintertime for folks.

> When I first started here, it was not unusual to have our educator go into a school and teach stuff. But now HIV/ AIDS is taught in the curriculum in the province. In all the schools in the province, it is in the curriculum. Certainly AIDS Saskatoon had a role in bringing this about, and also one of our earlier executive directors was on the committee that helped develop that, bring that into being.

5.5 Assuming Political Role

5.5.1 Political Role and Using the Media

Talking about the political role that AIDS Saskatoon assumed within the community is loaded with a sense of pride by the participants. All of participants of this study said that it had a significant impact on this perspective, and they particularly highlighted their success in moving both the public health and the provincial government to respond.

Back in the mid-90s a former executive director of AIDS Saskatoon with the help of other persons formed an organization called SAN – the Saskatchewan Aids Network. At that time there were up to thirteen groups in the province who were providing AIDS service of some kind, and he and some others in the city banded together all these groups to do political action, so they met for a while and they succeeded in getting funding (Participant number 3).

There are three different committees that the executive director is working on right now, the one that is heading up the west side clinic on 20th street with the health region, and the committee that is setting up the strategy for injection drug users in Saskatoon, and the ministerial committee on HIV/AIDS. All three of those are committees that will be studying varying levels of health policy. When he goes to those meetings, he takes with him the whole philosophy of AIDS Saskatoon, so it is not just him its all of us who have input that way (Participant number 3).

Locally just previous to this election in conjunction with Avenue Community Centre AIDS Saskatoon sent a request around to our MLA's asking for what their response should be, what Saskatchewan's response should be to growing HIV/AIDS and STI infection rates (Participant number 4).

The International AIDS Conference held in Toronto last summer, 2006 we had a staff member there. It was a whole bunch of people coming together and there was opportunity, obviously, to protest the Prime Minister's lack of involvement in that conference – and also to work to effect bigger change in our community (Participant number 4).

5.5.2 Supporters Inside Political Institutions

Surely, according to the participants, all the work that they succeeded in achieving throughout their movement's existence was never done in isolation. They had on one hand a very sympathetic media which really helped them to gain the status of this kind of legitimate organization, and on the other hand they have also a big line of supporting individuals both from the public and political organizations. As these participants elaborate in their testimonies:

We do have supporters inside the political system. There is one MLA that just is no longer an MLA, and also a couple of MLA's that come out when we do Tag

Day or AIDS Walk and different things like that, so yes. There are some politicians that are supportive and they also participate in some events that we organize (Participant number 4).

We have some MLA's that support AIDS Saskatoon financially. We do know MLA's like David Forbes, and we know Pat Atkinson and the premiere, Lorne Calvert. And he realizes in his riding, there are a lot of people who are marginalized in the Riversdale area in his riding and they are aware of what is going on with the AIDS Saskatoon's issues (Participant number 5).

5.5.3 AIDS Saskatoon as a Voice for those that have No Voice

Participants' statements that are mentioned below explain in what sense AIDS Saskatoon can be a voice for those that don't have voice through the media within the community. One of the reasons often mentioned is that AIDS Saskatoon worked with both local health districts and with the province as well. And it also works through national organizations because most of those organizations belong to the Canadian AIDS Society which lobbies on their behalf to the federal government and through such processes all the voices of those individuals that belonged to them are carried into different political arenas. The following statements make this clear:

Whenever AIDS Saskatoon is seen in the public eye I think that helps give a voice to the people that we provide service to (Participant number 3).

We used to have our annual Bid for Life which was an art auction every year. We used to get really good media coverage over that. We always get media coverage around Tag Day and around AIDS Walk and. This year when the grandmothers from Africa came here, we got good media coverage over that. They actually planted a cedar in our backyard and the media really, really liked that (Participant number 3).

Any time there is something in the media regarding HIV and AIDS, the media goes to local AIDS service organization and so it is always an opportunity to remind people that HIV and AIDS is an issue in Canada and as many people out there who are doing fine there are just many who are not doing fine, not getting access to anti-retrovirals, not getting access to basic necessities like food and

shelter. So AIDS Saskatoon does give a voice to people, because these people would get no real exposure otherwise (Participant number 2).

We do get opportunities to interviews for the paper. In the past year we have done an interview for the Star Phoenix and another one for The Sheaf around the services we provide and the realities of life with HIV here in Saskatoon (Participant number 4).

5.6 Health from Below Perspective

5.6.1 Saskatoon's West Side Clinic (alternative clinic)

Participants emphasized that there is still quite an undercurrent of fear and a lack of understanding, and to some degree hatred when it comes to dealing with people with AIDS in the community. And therefore the need for alternative medical spaces with more broadly-based and a little more mainstream approach is of great importance in the community. And their sense is that Saskatoon's west side clinic would serve the purpose. The following statements made by Participant number 4 help illustrate this:

> One of the things that really made me excited right now is the action to create a clinical setting in Saskatoon's west side on 20th street. That would be a sort of one-stop medical shop for HIV testing, but making it feel less like a medical centre and making it more like a community space, where you can come and get condoms, if you want and while you are there, you could get quick HIV testing to know whether or not you have HIV. And a little drop-in centre where you could hang out and where there would be somebody whose job is to check in with you, and maybe if they see you on the street later, sort of say 'hey, how's it going. So it is to create a little bit of a sense of community and be a place where people can actually access.

> This clinic on 20th street would have a doctor on a regular basis, so while on a drop center you just walk in and you could access that doctor. And you would be like it is hard to get across the bridge to get to you at the hospital there, but here I can talk to you and sort of say is it time for me to go on treatment how is that work. So that is kind of cool. I mean obviously health care services in general are usually run by large bureaucracies and things take a long time to change.

5.6.2 AIDS Saskatoon as a Health Social Movement

Participants' comments underline the importance of having such health social movements as AIDS Saskatoon, because people who are HIV positive, especially the ones who are marginalized, do not have an advocate in the community. Therefore when they are having difficulties accessing medical services or accessing financial resources they have no other place to turn. Most respondents stressed the fact that HIV positive individuals are still treated differently in the community and until that is changed it's important for AIDS Saskatoon to be around. The following quotations clarify this:

> If it wasn't for AIDS Saskatoon, I probably wouldn't be sitting here talking to you today. I would probably be dead somewhere. Where else is a person supposed to go? I mean, you can go to the Friendship Inn and get something to eat, or the Salvation Army for something similar. But for somebody who is first dealing with the illness, the concept of being infected with HIV, fears, confusion, and what's going to happen to him, needs something different that you cannot get even at the doctor's office. So if it wasn't for places like AIDS Saskatoon that could help you to be at peace with it, understand it and to deal with it - I don't know where else are you going to go (Participant number 6).

> It is very important for me to be in here because I know that if it wasn't for this place, I would be out there on the street. Not even knowing that I was giving it to others, and I would be "Oh, here use my spoon. I got a needle you can take it" (Participant number 7).

> It is important to have AIDS Saskatoon around because if you don't have that kind of network support, then your self-esteem will be low again. You need people that are there all the time, people that are so caring about you and want to visit you, have coffee with you, and give you a hug when you need one. This can not be fulfilled outside of AIDS Saskatoon (Participant number 8).

> Places like AIDS Saskatoon need to exist especially for people that are newly diagnosed. Like myself, when I was first diagnosed in 1997, had Aids Saskatoon not been here, I honestly don't think I would be in the position where I am today: to be clean and mothering my child (Participant number 9).

There isn't really any other place for people to turn to where you can socialize without being identified with your HIV status, and where you could say your opinion about what matters to you and be sure that you are being heard (Participant number 3).

5.6.3 Issues and Concerns in AIDS Saskatoon's Agenda

Significantly, participants pointed out the fact that people come to AIDS Saskatoon because it is a safe place and it is non-judgmental. They also noted how in some cases people with HIV/AID are not capable of going through the process of filling out forms, doing paperwork, making appointments, sitting in waiting rooms waiting to see officials. This is particularly so for those in marginalized groups who feel like they are looked down on, that they are judged, and that people don't really want to be around them. The following comments express concerns of this nature:

One of our concerns for a number of years is that some health care is not accessible to people, getting up to RUH is not easy for many people. They cannot afford to get there, so that makes it hard for them to keep their appointments (Participant number 4).

There are still vast numbers of family doctors who have very, very limited knowledge about HIV. And in fact at times we have had people phoning in and they have actually been given wrong information by their family doctors (Participant number 3).

There aren't enough really good family doctors who are well educated with HIV, even in Saskatoon. That's one issue for sure (Participant number 3).

I think we're always being challenged how we can do better as a agency with legislation like, fundraising issues, keeping AIDS Saskatoon going, and government policy, like, working with the provincial and federal government (Participant number 5).

5.7 Summary

This chapter is divided into five subsections. The first outlined emerging

discourses within AIDS Saskatoon. This part dealt with the steps AIDS Saskatoon took in extending the public sphere by creating autonomous spaces and promoting participatory communication in which all participants have stressed the importance of having a space within AIDS Saskatoon where people can meet and discuss their issues.

The second section underlined the empowerment and emancipation processes that AIDS Saskatoon engages in by offering a social network for support and advocacy, offering an environment for knowledge transmission so people can learn from each other's experiences and also by being a source of different types of information.

The third part showed the social role AIDS Saskatoon appropriated by being a entry point for people living with HIV and AIDS into the system, offering the means and the environment for peer support, and also by creating an atmosphere for reconstructing personality for newly diagnosed people with HIV.

The fourth part revealed the role AIDS Saskatoon assumes in redefining cultural norms through changing mainstream thinking. And also through challenging the health authority, winning some battles with the system and also causing the provincial government to respond.

The fifth part of this chapter gave details about the political role that AIDS Saskatoon assumes through using the media, and through having supporters inside political institutions, as well as being a voice for those do not have a voice.

The last section dealt with AIDS Saskatoon's position in regard to the health from below perspective by highlighting the stand AIDS Saskatoon takes concerning the need for alternative medical spaces with more broadly based mainstream approach such as the west side clinic. In this section the importance of having AIDS Saskatoon around for

people who are HIV positive, especially the marginalized ones who do not have an advocate in the community, was highlighted. The need for AIDS Saskatoon was especially important when marginalized people are having difficulties accessing medical services or accessing financial resources. These points help describe the position that social movements like AIDS Saskatoon assume within the Canadian civil society.

CHAPTER 6: DISCUSSION

6.1 Introduction

Health social movements groups such as AIDS Saskatoon knowingly or unknowingly engage in shifting power relations by pressuring health authorities and empowering their members to gain more rights. They also question temporary democratic decision-making in which science and expertise are privileged in an uncritical fashion and thereby exclude the public from the whole process.

According to Habermas, decision-making processes are narrowed when technical issues are excluded from the public domain. In other words, concentrating the power of decision-making in the hands of experts can diminish democratic participation in the public sphere. Health social movements like AIDS Saskatoon are well positioned to participate in correcting this by not taking the role of experts but rather pushing policy makers to make socially informed decisions. Giving the nature of contemporary Western democracies, social movements that exist out side the system have the capacity to push to extend the public sphere and the democratization of the system.

This study incorporated a Habermasian approach that helps understand why social movements come into being and also how they can be seen as a positive response to the pressures of Lifeworld colonization and cultural deprivation. Supplementing this approach with the typology of politics introduced by Cohen and Arato facilitated answering the question about whether AIDS Saskatoon is a defensive or offensive movement.

6.2 AIDS Saskatoon as a Social Movement?

The first part of the analysis highlighted how AIDS Saskatoon is evidencing a

true new social movement character. AIDS Saskatoon came to being as a result of a long

process of collective action which was started almost 23 years ago. Also AIDS Saskatoon

is not an isolated group of individuals. It is a part and works collectively with a bigger

AIDS social movement that encompasses many AIDS groups all over Canada. The first

part of the analysis also showed how members of AIDS Saskatoon come together with

different identities and orientations to develop a collective identity and a sense of

belongingness, and common understanding, while maintaining at the same time their

specificity and distinctive characters. AIDS Saskatoon stands outside of the system

(Della, and Diani, 1999), it is concerned with the quality of life (Offe, 1985; Touraine

1985), and it challenges political and health care system in order for people living with

AIDS gain control over their lives and bodies (Habermas, 1981; Cohen, 1995).

6.2.1 Working out of the System

AIDS Saskatoon people are fully aware of their role as a civil society organization

that is not affiliated with any of the state's institutions. This was apparent in the

statements of both the founders and current staff members of AIDS Saskatoon.

Participant number 3 made this clear when he/she said

> AIDS Saskatoon is a non-government organization, or a community based
> organization is the other term we use.

Participant number 4 and 1 both made a similar point:

> My perception of AIDS Saskatoon would be it is a non-governmental
> organization that has come into being as a result of a social movement (Participant
> number 4).

> We had to have some legitimacy. As a group you need to be recognized legally as
> a social being, in order to be able to deal with the system (Participant number 1).

6.2.2 Challenging the Dominant System

Through the analysis of participants' statements, this study revealed how AIDS Saskatoon resists the extension of the instrumental rationality and defends the quality of life of its members. This was clear by the mobilizing activities of AIDS Saskatoon against certain policies that were produced by the health care system without people living with AIDS being part of the decision making process. Anonymous versus confidential testing, as well as curriculum change, are two good examples of such efforts made by AIDS Saskatoon. Participant number 1 explained the anonymous versus confidential testing incident when he/she said "because of the severe stigma, and potential discrimination, having it reportable it would discourage people from being tested" so they took a strong position to protect the identities of persons who tested positive.

Participant number 2 explained the change of the curriculum incident when he/she described the work and the lobbying done to change how the curriculum development and delivery.

6.2.3 Concern with the Quality of Life

As it has been shown, AIDS Saskatoon demonstrates one of the inherent features of new social movements, namely, a concern with the quality of life rather than material distribution. One clear examples of this is found in Participant number 2's statements related to how AIDS Saskatoon managed to push the Department of Community Resources to designate a case worker for people who were HIV positive, which meant this person would be well educated about HIV and AIDS, and with the issues people

living with AIDS face, in order to deal with them more appropriately.

6.3 Lifeworld Colonization and the Rise of AIDS Saskatoon

Through the analysis of interview data I described a twofold link between the colonization of the life-world and the rise of AIDS Saskatoon. First, the administrative system was indifferent to public opinion during the 1980s, and as a result of the colonization process the public sphere was eroded. Second, the colonization of the life-world of people living with HIV/AIDS was the cause of some strains that motivated them mobilize. The following points summarize some of the links between the colonization of the life-world and the rise of AIDS Saskatoon.

6.3.1 Stigmatization

Stigmatization that comes from the health care system's staff and other official organizations is one way the voice of the life-world is suppressed and an indication of distorted communication patterns. Many participants pointed to this fact through their testimonies. Participant number 3, for example, said "There are medical care staff that were not always appropriate when it comes to dealing with those who are HIV positive". Participant number 10 highlighted the negative implications for employment and all other aspects of life of becoming vocal and visible with HIV status. Participant number 2 talked about widespread prejudiced opinions held about people with HIV/AIDS: everybody - even social work students - believe those living with AIDS somehow must have done something to deserve ending up where they are.

6.3.2 Doctor Patient Relationship

As it is explained in section 4.3.2, doctor patient communication makes clear the struggle between the voice of medicine and the voice of the life-world and, as a result,

how the voice of the life-world is suppressed and fragmented. Participant number 3 made this point: "Many of our people feel often that they are not listened to when they are in the health care system". This leads to a great deal of discrimination and negative judgment about people who use street drugs, or who have been involved in street life in any way. Participant number 4 mentioned that some people feel they are not valued as persons by some health care providers. Rather, they are seen only as either a client or a consumer. Participant number 1 underscored the point: "A lot of especially homosexual men and people with AIDS did not trust the mainstream medical system because of their attitude regarding homosexuality".

6.3.3 Health Insurance and Prescription Costs

Trouble accessing health insurance and high prescription costs are factors that push people to get together and mobilize in pursuit of their needs and interests and against lifeworld colonization. The extension of instrumental rationality into more and more spheres of life results in lifeworld colonization wherein relationships based on communicative action oriented to achieving mutual understanding, trust and solidarity are replaced by relationships based on goal oriented interactions steered by the media of money and power and oriented towards success not understanding. Under such conditions those with the most money and or power win and that is the goal of the process (Habermas, 1979). Participants spoke to both issues.

In regard to the prescription costs, for example, Participant number 6 asked how a person is supposed to work and pay for a prescription that's six hundred and fifty dollars a month? Participant number 10 stressed the same fact saying he/she could not afford one prescription that was eight hundred and some dollars a month.

In regard to the health insurance, Participant number 6 summarized the matter when he/she mentioned how he/she can't get access to the health benefits that the company he/she works for offers because if they found out that he/she was HIV positive he/she would be fired. Participant number 10 also explained how because of his/her AIDS status he/she is not insurable.

6.4 Types of politics of AIDS Saskatoon

The members of AIDS Saskatoon are without doubt intentionally working to decolonize the system by inserting new values democratizing public spaces. This can be seen in three of AIDS Saskatoon' activities:

- by creating communicative space outside of the system

- by pushing the issue of AIDS into the flagging public sphere

- by reconstructing the relationship between the institutions of the political sphere and civil society.

6.4.1 Democratization and the 'Politics of identity'

AIDS Saskatoon contributes to institutionalizing communicative action and resisting the colonization of the lifeworld by sustaining debates in part of the public sphere, advocating skepticism toward medical claims, and insisting on the patient's decision-making autonomy.

AIDS Saskatoon also provided settings for the face-to-face interactions that are so important in drawing individuals into activism. Overall, looking at AIDS Saskatoon, it is clear that health social movements are fundamentally engaged in reforming reality. All participants highlighted this fact by emphasizing there is no other place for people with AIDS to turn, where they can socialize without being identified with their HIV status, and

where they can state their needs, interests and preferences and be sure they are being heard.

6.4.2 Empowerment and Emancipation and the 'Politics of identity'

The analysis part showed how AIDS Saskatoon empowered people with HIV/AIDS by making them feel more in control of their condition by operating as a pressure group on professional and public authorities, by offering support at the local level, and by asserting that community-based AIDS organizations have the expertise to define public health constructs. Participants expressed these views when they talked about how they dealt with a variety of social issues, including raising awareness about discrimination and taking positions on anonymous versus confidential testing, and on whether hospital staff should know whether patients are HIV/AIDS positive.

6.4.3 Offensive Mode 'Politics of influence and inclusion'

The analysis showed how AIDS Saskatoon seeks to establish new agendas, (section 5.6) and conquer new territory (section 5.4) rather than just defending existing social and cultural patterns. This is accomplished by being part of a political process used by marginalized groups to pursue their needs, interests and preferences. Participants made this clear when they mentioned activates such as the one that took place in the mid-90s involving the executive director of AIDS Saskatoon along with other thirteen groups forming an organization called the Saskatchewan Aids Network to do political action

6.5 Conclusion

The main character of health social movements like AIDS Saskatoon is momentous in pointing out the power of civil society organizations. There is no doubt that this movement is generating an alternative sphere that strengthens civil society

against the dominant cultural model. Nevertheless, its aim is the democratization and emancipation of system institutions without orienting itself towards capturing state's power.

Participants in AIDS Saskatoon are life-world oriented and they seem to be aware of their ability to make a difference within Canadian society. In regard to the question how AIDS Saskatoon was formed, the analysis showed patterns of colonization of the lifeworld of people with HIV/AIDS that are linked into the rise of the AIDS Saskatoon.

In terms of the limitation of the study, the new social movement analysts in general and Habermas in particular are criticized for their focus exclusively on collective identity, symbolic challenges and post-material values and for the degree to which they ignore issues relating to material redistribution, structural inequality and so forth. Some analysts like Calhoun (1994, p. 22) have argued that some contemporary movements seem more old than they do new. Meaning they are less concerned with post-material struggles relating to the quality of life and more concerned with traditional issues such as material distribution, political opposition and citizenship rights. Shakespeare (1993, p. 25), for example, argued that the disability movement is still concerned with liberation rather than with post-material values. Members of this movement develop their collective identity around unemployment, homelessness or similar newly relevant survival issues. It appears that there are some movements that contain a complex mix of traditional and novel elements. AIDS Saskatoon in some aspects of its work is concerned with issues like unemployment and homelessness for some of its members, however, its primary concerns do not revolve around these issues.

This study examined how AIDS Saskatoon was a creative response to the

processes of lifeworld colonization. The findings support the position that AIDS

Saskatoon is a type of new social movement that has an organizational form conducive to

both defensive and offensive actions. In conclusion, under the current state of modernity

social movements like AIDS Saskatoon are well positioned to promote institutional

change within civil society and to further develop the positive potential of modernity.

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Appendix: A

Letter of Introduction and Explanation of Research Project

INTRODUCTION AND EXPLANATION OF RESEARCH PROJECT

<u>**New Social Movements in Canadian Health Domain:**</u>
<u>**AIDS Saskatoon as a Case Study**</u>

As a result of your participation in the New Social Movements in Canadian Health Domain: AIDS Saskatoon as a Case Study research, you have been selected to participate in a research study; a study which will contribute to a M.A. thesis for the Department of Sociology at the University of Saskatchewan. Your researcher is Auob Alashegam, a third year graduate student from the Department of Sociology.

The purpose of this thesis research is finding out what are the conditions which made it possible for AIDS Saskatoon to come into being, exploring in what aspects AIDS Saskatoon participate in shaping the society, and examining whether it is a force for democratization and emancipation within the Canadian context.

The interview will take approximately one hour, and will be conducted at a time and location convenient to you. Your identity and responses will remain completely confidential, and you may withdraw from the process at any time. I will be contacting you within the next week to confirm your participation. Please feel free to contact me or my research supervisors at the contact information below with any further questions you may have. Your contribution is greatly appreciated.

Thank-you,

Sincerely,

Auob alashegam

Letter of Consent

LETTER OF CONSENT

You are invited to participate in a study called: *New Social Movements in Canadian Health Domain: AIDS Saskatoon as a Case Study*. Please read this form carefully, and feel free to ask any questions you might have.

Your interviewer is Auob Alashegam, a Masters student of Sociology at the University of Saskatchewan. This study is about social movements in the Canadian health domain. The purpose of this thesis research is finding out what are the conditions which made it possible for AIDS Saskatoon to come into being, exploring in what aspects AIDS Saskatoon participate in shaping the society and examining whether it is a force for democratization and emancipation within the Canadian context. You have been selected as a result of your involvement, or being part of AIDS Saskatoon.

Selected participants that have been invited to participate in the interview process represent a range of diverse sectors involved in AIDS Saskatoon's work. The interview will take place at a convenient location and will take approximately 60 minutes of your time. There are no perceived risks that may result from your involvement in this study. In order to ensure confidentiality, no identifying information that may link you to your responses will be used in the final reporting of research results. However, as direct quotations may be required, you will be given the opportunity to review the complete transcription of your interview and asked to sign the attached Transcript Release Form.

You are under no obligation to reply to any particular question which may make you feel uncomfortable. Participation in the interview process is complete voluntary. You may withdraw from the process at any time. If you choose to withdraw from the process, your responses will be destroyed from the database. After the interview, you will be given the opportunity to review the transcript of your responses, and to add, alter, or delete information as you see fit. Transcripts of

the interview will be safely stored at the Department of Sociology, according to the University of Saskatchewan's standard research procedures and protocols.

The findings of this research will be included in a M.A. thesis for the Department of Sociology, at the University of Saskatchewan. Once successfully defended and bound, the thesis will be available from the Sociology department, the Community-University Institute for Social Research, or online at http://library2.usask.ca/etd.

If you have any questions concerning the study, you are free to contact the researcher or the research supervisors at the numbers provided.

I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactory. I consent to participate in the study described above, and I understand that I may withdraw this consent at any time. I have received a copy of this consent form for my records.

_____   _____

(Name of Participant)   (Date)

_____   _____

(Signature of Participant)   (Signature of Researcher)

This study has been reviewed and approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on (XXXX). Contact the Ethics Office at 966-2084 with any questions regarding participant rights.

Appendix: C

Transcript Release form

TRANSCRPIT RELEASE FORM

Study Title:

New Social Movements in Canadian Health Domain,AIDS Saskatoon as a Case Study

Researcher: Auob Alashegam

I, _____, have been given the opportunity to review the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with <u>Auob Alashegam</u> from the <u>University of Saskatchewan</u>. I hereby authorize the release of this transcript to <u>Auob Alashegam</u> to be used in the manner described in the consent form. I have received a copy of this Transcript Release Form for my own records.

_____   _____
Name of Participant   Date

_____   _____
Signature of Participant   Signature of researcher