STIGMA AND WOMEN LIVING WITH HIV

A CO-OPERATIVE INQUIRY

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Abstract

This thesis explores the impact of stigma on women in New Zealand living with HIV through the use of co-operative inquiry, an innovative, participatory, action-based and somewhat revolutionary, research method. Through the process of sharing experiences, reflection and discussion, participants were encouraged to learn to interpret meaning and gain a better understanding of their world. As a result of working through an agreed set of actions this process lead to personal transformations and consciousness-raising for all those who took part, including myself.

The innovative method of co-operative inquiry is about discovery and learning. It is not about confirming or validating previous theories or hypothesis. All participants, including the researcher, were women living with HIV, who worked together as co-participants in a research project which was done 'with' rather than 'about' those who took part and was based on feminist grounded theory.

Key findings are significant not only for participants of this research but also for future governmental and community interventions and policies in regards to HIV awareness and education in New Zealand. Increasing awareness and education will reduce the transmission of HIV and will assist with destigmatising HIV, an empowering process for people living with or affected by HIV or AIDS.

Acknowledgments

Prologue

In my role as National Coordinator for Positive Women Inc., I often hear stories about the impact living with HIV has on the lives of women. It was one such story which planted the seed for this project.

A woman, who had been living with HIV for more than 10 years at the time we spoke, shared with me how her (HIV-) partner wanted to tell his adult children from a prior marriage, about her HIV status. She commented how this was causing her considerable anxiety. She said she did not want him to do this as she felt 'so ashamed' (of having HIV).

I was both surprised and astonished by her revelation. This woman had nothing to be ashamed about! The more I thought about it I realised I probably should not have been surprised. Although she had been a member of Positive Women Inc. and I had known her for many years, I only knew her by her first name as she had never in all that time felt comfortable to disclose her surname for fear of revealing her full identify, even to other women who also lived with HIV.

While this is only one story, over the years I have heard many very similar stories of women feeling ashamed, frightened, depressed and isolated. Having been HIV+ myself since 1988, I thought about my own position in this regard and realised I too had similar feelings.

What were we all afraid of? What were we ashamed of, fearful of? These questions persisted and I realised these feelings were directly related to the stigma associated to HIV. Yet I did not fully understand how 'stigma' was manifested and I was keen to investigate it further. This personal investigation underpinned the initial motivation for the project and consequently has been both a journey of self exploration and academic inquiry.

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List of (Figures, Tables or Plates)

Glossary

AIDS   *Acquired Immune Deficiently Syndrome*:   When the HIV virus has managed to kill off most of a person's immune system

ARV   *Antiretroviral Medication*: A combination of medication used to help manage HIV. The aim of these drugs is to stop HIV from replication and infecting new cells in the body.

HAART   *Highly Active Anti-Retroviral Treatment*: A combination of three or more drugs

HIV   *Human Immunodeficiency Virus*: A virus which attacks the cells in the immune system of human beings.

HIV+   *Human Immunodeficiency Virus positive:* A person who has the HIV virus

IDU   *Intravenous Drug User***:** A term generally applied to people who inject themselves for recreational drug use

OI's   *Opportunistic Infections (or Illnesses)*: An infection or illness which attacks the body when the immune system is compromised and often so weak that the immune system is unable to fight off the illness.

Stigma   A mark or sign of disgrace or discredit (Fowler & Fowler, 1995).

Pakeha   Word used to refer to non Maori New Zealanders

PLWH   People living with HIV (or AIDS)

1 Introduction

This research project investigates the impact that living with a stigmatising disease such as HIV has on women in a New Zealand context. It also grapples with ways of coping with stigma in order to minimize its impact on the quality of life of women who have acquired HIV. An ideal outcome would be the eradication of stigma completely or at least to find ways in which to educate communities to accept its members without prejudice.

HIV in New Zealand, even after 25 years, still predominantly has a focus on men so I felt strongly about doing a project which placed women at the centre of the study. Wanting to do research which was participatory, fully inclusive and action focused, co-operative inquiry was chosen as an appropriate research method. Co-operative inquiry is a way of doing research *with* people where the roles of the researcher and the participants are integrated. It does not start with a hypothesis to be proven or disproven and no real structured research questions, however the participants collectively shaped and formulated a suitable structure as they moved through the inquiry process.

There has been no prior research on stigma and women living with HIV in New Zealand using co-operative inquiry as a methodology so this pioneering research also evaluates the effectiveness of co-operative inquiry as a research method in this context. Through its repeated cycles of reflection and action it was hoped the project would have an impact on the participants and while this technique was not meant as any form of 'therapy', because of its transformative nature, it was hoped the participants would benefit from the process and find it useful in terms of improvement of the quality of their lives.

1.1 Methodological issue

Co-operative inquiry is not a process which is meant to be analysed. There are no theories or hypotheses to prove or disprove (Heron, 1996; Sontag 2001). The complexities of this were evident when it came to writing up the thesis, as critical analysis is a major component at a masters degree level. In this thesis the critical analysis has been replaced with a reflective analysis which was done as a meta-reflection by the researcher after going over the material following the group inquiry sessions.

1.2 Document outline

It was felt some background information around HIV and AIDS would be useful to provide the reader with a general understanding and to provide further context to the project. This is outlined in chapter 3 which provides a brief history and the current global and national positioning of HIV and AIDS. Some background information about Positive

Women Inc. has also been provided as this was the organisation from which the participants were recruited.

A comprehensive literature review is provided in chapter 4 and chapter 5 outlines the methodology, ethical considerations, recruitment of participants and methods of data collection used for the project, while chapter 6 provides information on the theoretical underpinning of the project.

Chapter 7 provides a discussion on the practical application of co-operative inquiry and the actions undertaken by the participants in the context of this project which is explained in a session by session breakdown.

Chapter 8 is where this thesis deviates from the true form of co-operative inquiry in that co-operative inquiry is not designed for analysis by the researcher. This chapter focuses on themes which emerged over the five inquiry sessions and each theme has been divided into three parts, 1) Inquiry Reflections, 2) Reflective Analysis and 3) Conclusions.

The Inquiry reflections consist of quotes from the participants which have been included to ensure the voices of the participants are heard and provide context to substantiate the reflective analysis.

The analysis was based on the researcher's interpretation of what the participants said during the inquiry sessions and was compared to findings from the literature review. In light of this deviation, the reader needs to be aware that the reflective analysis may not necessarily fully reflect the thoughts of the participants. If this project had been able to continue through the usual co-operative inquiry cycles of action and reflection, and was not being done for a masters degree which required a 'critical analysis', participants themselves would co-write this part. Due to these constraints this was not possible, but may happen in the future in a less formal shape.

Chapter 9 provides feedback given by participants seven months after the co-operative inquiry sessions were finished in an attempt to identify how, or if, participating in the co-operative inquiry had made any impact or transformed the lives of the participants in any way. Chapter 10 draws the research together and also includes recommendations and future actions.

The appendices include copies of all documentation used throughout the process of this project including copies of the mind-maps used to record data.

2 Background

2.1 Introduction

This chapter includes background information to provide context for the project. This will consist of a brief history and a very simplified definition of HIV and AIDS. It will also provide an explanation of the significance of both the CD4 and viral load. A simplified approach has been chosen so as not to divert from the actual topic matter which is about stigma and HIV and not the medical and clinical manifestation of HIV and AIDS.

Statistics have been provided to highlight the impact of HIV in other countries of the world and in New Zealand as a comparison to provide both a global and national context. Also included is some back-ground information on Positive Women Inc., the organisation from which the participants for this project were recruited.

2.2 History of HIV and AIDS

The AIDS epidemic was first brought to the attention of the world in America in 1981 when doctors in Los Angeles noticed a strange new disease which was killing homosexual men. Although evidence of HIV infection was actually detected in a blood sample taken in Zaire as early as 1959 but this was not able to be confirmed until HIV antibody testing was perfected in 1986 (Thomas, 1999).

It is thought HIV may initially have evolved in Africa among people who hunted chimpanzees and a species of monkey called the sooty magabeys. A virus called SIV which stands for Simian (ape/monkey) Immunodeficiency Virus was detected in these animals but the virus did not affect them in any harmful way. It seems likely the hunters of these monkeys contracted SIV through contact with monkey blood. It is thought once the SIV virus infected humans, it mutated into HIV, which was then transmitted from human to human (Thomas, 1999).

Gradually the virus was transmitted to people from Europe and America, initially amongst homosexual men, which is why in western countries AIDS was initially labeled as a 'gay disease'. By 1990 more than 10 million people globally were estimated to be living with HIV or AIDS. This figure rose to over 24 million by 1996 and it was becoming apparent HIV was affecting all sectors of the community, not just gay men (Thomas, 1999).

2.3 HIV and AIDS explained

HIV is the term given to a virus called the Human Immunodeficiency Virus which attacks the immune system by destroying the cells which fight off illnesses and infections. These cells are commonly referred to as CD4 cells and are explained in more detail in chapter 3.4.

AIDS stands for Acquired Immune Deficiency Syndrome. This is when the Human Immunodeficiency Virus has attacked and weakened the immune system to such a degree it can no longer fight off illnesses and infections and a person can become vulnerable to 'opportunistic infections' (OI's).

Opportunistic infections are a collection of specific illnesses or infections which happen when the immune system has been damaged to such an extent that it is no longer able to fight off infections which can result in death. Basically AIDS is the end stage.

There is no treatment or medication which can get rid of HIV from the body but there are now a number of very excellent medications which are used to manage the virus limiting the damage it can do to the immune system. These medicines are called, antiretroviral's (ARV's). Their main purpose is to stop HIV from replicating and further damaging the immune system.

HIV treatments have improved dramatically over the past 10 years with new drugs becoming available all the time. Although there is still no cure, life expectancy for many people living with HIV has improved immensely as the medications slow down the progression from HIV to AIDS. People with HIV can expect to live for 20 or 30 years or longer and the incidence of some life threatening illnesses have declined by as much as 90% (AFAO & NAPWA, 2005).

There are two very important factors which play a significant role in both the progression and management of HIV. These are CD4 cells and the viral load.

2.4 CD4 and Viral Load

A large part of the immune system is made up of white blood cells called CD4 or T4 cells and these are the cells which HIV attacks. Usually the immune system is able to fight off viruses but this is not the case with HIV, instead the virus attacks the CD4 cell, reproducing itself in the process. Once the virus has destroyed the CD4 cell it enters back into the blood stream and goes in search of more CD4 cells. This cycle is continuously repeated, each time the virus is reproducing and destroying the CD4 cells

until eventually it kills off all the CD4 cells in the body leaving the immune system weak. It is at this stage other infections (OI's) begin to attack the body and because the immune system is unable to fight off these infections, a person will become very sick and may even die. This stage is called AIDS (AFAO & NAPWA, 2005).

The viral load refers to the amount of HIV in the blood at any one time. Without medication, HIV constantly makes copies of itself. The more virus there is in the blood, the more damage it does to the immune system. The aim for a person living with HIV is to maintain a low viral load so the body can regenerate CD4 cells to maintain a strong immune system.

It is very important for people living with HIV to monitor both their CD4 and viral load levels as these are significant measures in determining when a person may need to consider starting on ARV treatment. This can be done by a very simple blood test.

People who do not have HIV will generally have a CD4 count between 500 - 1200. In the case of a person with HIV, should their CD4 count go below 300, it is generally recommended they start, or at least consider starting, on ARV treatment.

On a global scale, HIV is one of the most devastating diseases in the world today.

2.5   Global Statistics on HIV and AIDS

Statistics released by UNAIDS indicate that globally there were around 33 million people living with HIV at the end of 2007 as can be seen in Figure 1. Of these 15.5 million were women over the age of 15 and 2 million were children under the age of 15. This highlights that just over 17 million people affected by HIV world-wide in 2007 were women and children (UNAIDS, 2008). A significant statistic considering how acutely stigmatised HIV continues to be.

During this same period, there were 2.7 million new HIV diagnoses while the number of people dying as a result of an AIDS related illnesses rose from 1.7 million in 2001 to 2 million (UNAIDS, 2008).

Even though many people are still dying, there are however more new HIV diagnoses than AIDS related deaths, which means there are now more people than ever living with HIV (UNAIDS, 2008) and affected by stigma than ever before.
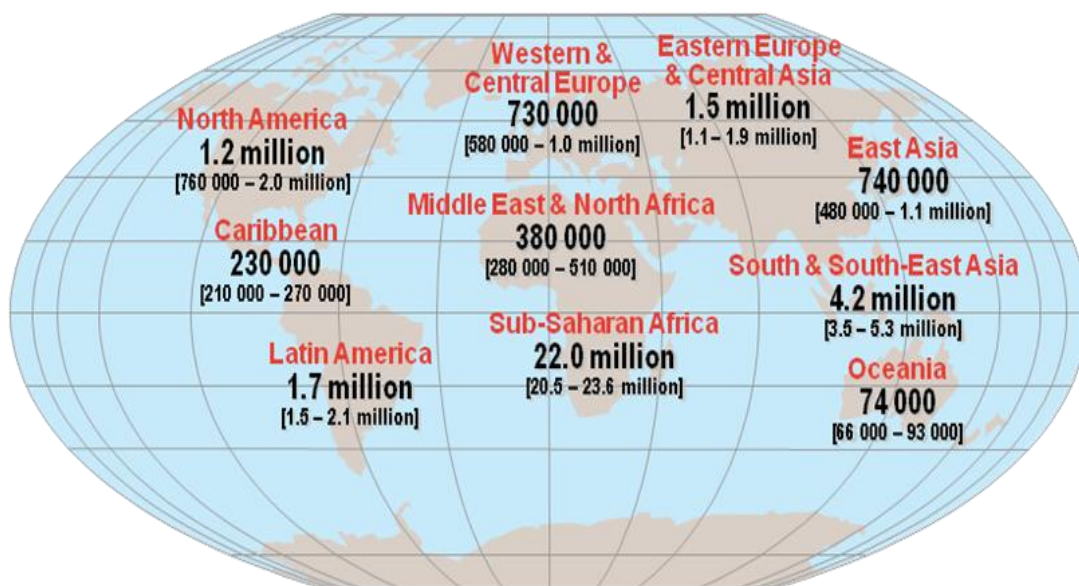
Figure 1: Global Statistics on HIV and AIDS
(UNAIDS, 2008)

2.6 Current New Zealand Statistics

Compared to global figures, HIV prevalence in New Zealand is relatively low; however numbers of HIV diagnoses continue to increase.

Once considered to be a disease affecting mostly men-who-have-sex-with-men, intravenous drug users and sex workers, and while HIV does still affect homosexual men more than any other sector of the community in New Zealand, HIV diagnoses in the heterosexual community are steadily increasing as can be seen in Figure 2 below.

This graph shows the number of people diagnosed with HIV in New Zealand through antibody testing by year of diagnosis and means of infection, although infection may have occurred sometime before diagnosis (McAllister, 2009). The reason for the time lapse between contraction and diagnosis is because people, particularly heterosexuals, are often not aware they are at risk of contracting HIV especially as initially there are no outward symptoms. Even if HIV is suspected, many people are afraid and defer getting tested, often because of the fear and the continued stigma associated with an HIV diagnoses.
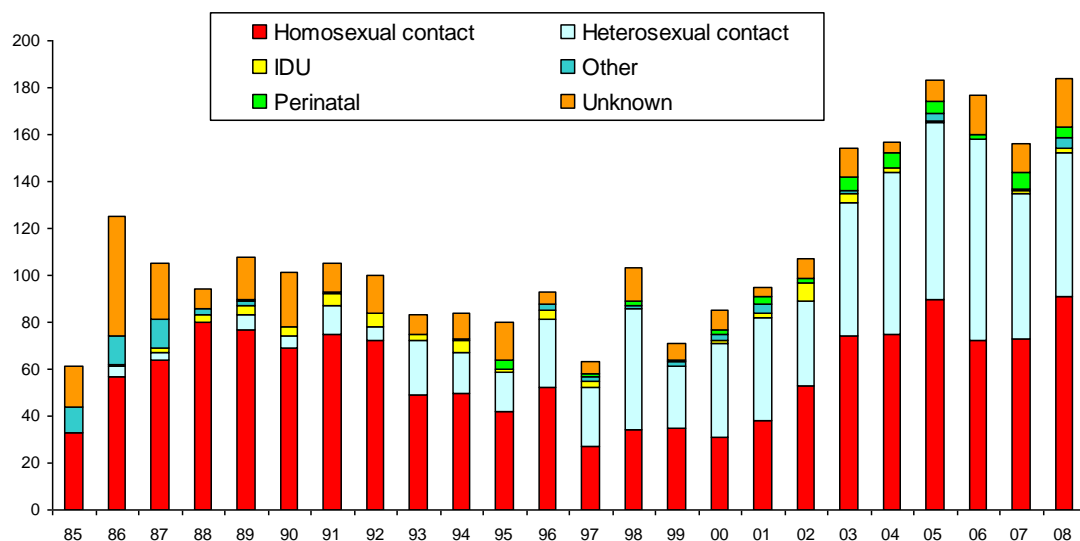
Figure 2: New Zealand Statistics on HIV and AIDS

(McAllister, 2009)

2.7   Positive Women Incorporated.

Positive Women Inc. is a peer support organisation for Women and Families in New Zealand living with HIV or AIDS. It was first established in 1990 as a response to the increasing numbers of women being diagnosed with HIV.

While HIV prevalence in New Zealand is relatively low compared to some places in the world (as can be seen in Figures 1 & 2), there has however been a slow and steady increase in HIV diagnoses in New Zealand over the past 23 years. In particular we are seeing an increase in the number of heterosexual men and women being diagnosed. Since recording of tests first began in 1985 by the AIDS Epidemiology Department at Otago University in Canterbury there have been 450 women diagnosed with HIV (McAllister, 2009). An HIV diagnosis is particularly traumatic and consequently many of these women seek support. Positive Women Inc. is one organisation which women living with HIV can turn to.

As previously mentioned, in the early days of the epidemic the virus affected mainly gay men, and consequently most of the services, understandably, focused on meeting the needs of gay men. With a small emerging number of women being diagnosed, these women felt the existing service providers did not meet their needs and as a response established Positive Women. At that time is was fundamentally a small group of women who got together to provide moral support and was run on a voluntary basis with assistance from the Community AIDS Resource Team which worked alongside the infectious diseases clinic at Auckland Hospital.

Positive Women Inc., became an incorporated society in 2000 and continued to be run on a volunteer bases. This relied heavily on women stepping up to the role of organizing meetings, events and activities, when and if they had the time, energy and good health.

In 2004 Positive Women Inc., was in jeopardy of collapsing after the resignation of the two voluntary coordinators. The members of the organisation held a special meeting in April 2004 and decided the organisation needed to employ a full time, paid, National Coordinator to insure the sustainability of the organisation. This person was employed in September 2004. While being HIV+ was not a requirement for the job, it so happened the successful applicant (myself), was a woman living with HIV.

With the employment of a full time coordinator Positive Women Inc. has subsequently been in a better position to establish itself as an important support network for women and families in New Zealand living with HIV or AIDS as well as working to raise HIV

awareness within New Zealand, predominantly targeting the heterosexual community as they saw a gap in this area (Bruning, 2008).

2.8 Summary

While the information on HIV and AIDS provided in this chapter is relatively simplistic it needs to be understood both are very scientific and complex diseases and I do not wish to diminish the complexities of the disease in anyway. However, I did not feel complex scientific explanations which might deviate from the primary focus of the project were required. The intention has been to present the reader with an introduction to HIV and where it is located globally to provide context for this project. [1]

It is evident by the statistics provided in this chapter that HIV is a global epidemic. What is curious however is even after being around for over 25 years and affecting so many people around the world, old paradigms of stigma and discrimination still persist and seem unable to evolve at the same pace as the progression of the epidemic.

Stigmatisation of specific people or groups has been occurring long before HIV and AIDS were known to exist yet HIV and AIDS have managed to elevate stigma to new heights as it is ingrained in deep-rooted social fears and anxieties.

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[1] There are many excellent sources which can provide an overview of the complexity of HIV. For example: Thomas, M. (1999). *AIDS explained*. Auckland Mark Thomas Department of Molecular Medicine, Auckland School of Medicine.

3 Literature Review

3.1 Introduction

There is limited literature on HIV and women in New Zealand, and no current literature on '*stigma and women living with HIV*' from a New Zealand perspective. There is however substantial literature on the subject from other parts of the world hence much of the literature for this review is drawn from either an American or African perspective (Abel, 2007; Gibson & Rohleder, 2006; Hoffman, Murphy, & Roberts, 2002; Hutchinson & Ingram, 1999; Lekas, Schrimshaw, & Siegel, 2006; Pretter, Schrimshaw & Siegel 2005). Also there is an increasing amount of research beginning to come out of Australia (Barton, Persson, & Richards, 2006) and this body of research has been pertinent to this project.

The literature review attempts to define or conceptualize stigma from a general viewpoint and then investigates the relationship between stigma and HIV (and AIDS). The review then continues to explore the impact which stigma has on people, but specifically women living with HIV and includes an examination of the coping strategies put in place to enable those affected to manage both the societal and psychological consequences of living with HIV related stigma.

The internalisation of stigma by those affected is a common phenomenon. This review investigates how the internalisation of stigma is manifested and discusses the consequences for (and to) both society and those living with the stigma of HIV such as sex, relationships and discrimination.
The review also investigates literature on possible actions and interventions to help reduce stigma and concludes with a summary of findings.

3.2 Defining and Conceptualizing Stigma

Attempts to define or provide a definition of the *concept* of stigma often do not provide a very comprehensive or explicit description. The problem is that the concept of stigma has been applied to a vast selection of situations with circumstances often being very different to each other resulting in conclusions being reached in different ways.

Goffman (1963) identified stigma as "*an attribute that is deeply discrediting*", and states stigma is conceptualised by society about what it *believes* to be *different* or *deviant*. These concepts are then incorporated into society through rules and restrictions which

result in the construction of what Goffman describes as a '*spoiled identity*' for the person or people concerned (Goffman, 1963).

Similar to Goffman (1963), Chan & Reidpath (2005) describe stigmatising as a process of '*blaming'* or '*marking'* people who are judged to be unworthy of social investment and by attributing blame to an individual or a specific group, it allows the unaffected members of society to relinquish any sense of responsibility and to ignore or isolate the affected person or group (Chan & Reidpath, 2005).

While the works of Goffman (1963) and Chan & Reidpath (2005) do recognise to some extent that stigma is socially constructed, their focus is predominantly around the effects and behaviours of those affected rather than the social construction of stigma. Looking at stigma from this perspective has resulted in stigma being seen as something *in* the stigmatised person rather than a label that others attach *to* a person and where people are thought to *be* the thing they are labeled. An example of this can be seen with people affected by schizophrenia who are often labeled as "*schizophrenics*" rather than being described as a person *who has* schizophrenia. (Link & Phelan, 2001).

In their attempt to conceptualize stigma Link and Phelan (2001) believe stigma is identified when five key components exist.

> 1) When people distinguish and label human differences.
> 2) When dominant cultural beliefs link labeled persons to undesirable characteristics to negative stereotypes.
> 3) When labeled persons are placed in distinct categories so as to accomplish some degree of separation of "us" and "them".
> 4) When labeled persons experience status loss and discrimination which leads to unequal outcomes.
> 5) That stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination (Link & Phelan, 2001).

This definition emphasizes the association between labels and stereotypes as a major aspect in the psychological study of stigma. When placed in group situations people will create status hierarchies and the result of stereotyping and applying labels to specific people is that they are then assigned to a specific status within the social hierarchy. Stigmatised people are generally placed lower in this hierarchy and as well as being stigmatised by society this hierarchal placement has an effect on those being stigmatised

as their self esteem and perceived life chances are challenged because they feel others 'look down on them' (Link & Phelan, 2001).

Ingram & Schneider (1993) take the social conceptualizing of stigma one step further by arguing that society constructs what is called "*target populations*" which are based on perceived *political power*. These target populations are shaped by history, culture, religion and politics and can be either positive or negative. Positive social constructions might include groups of people who are considered "intelligent", "deserving" and "honest" and are considered to be powerful while negative constructions might include groups of people who are thought to be "stupid", "undeserving" or "dishonest" and thus considered as weak (Figure 3). It is also important to realise perceptions of stigma are always contextual, for example a communist in China will probably be in a strong positive quadrant.

Constructions

	Positive	**Negative**
Strong	***Advantaged*** The elderly Business Veterans Scientists	***Contenders*** The Rich Big Unions Minorities Cultural elites Moral majority
Weak	***Dependents*** Children Mothers Disabled	***Deviants*** Criminals Drug addicts Communists Flag Burners Gangs

Power (vertical axis label)

Figure 3: Social Constructions and Political Power:
Types of Target Populations
(Ingram & Schneider, 1993)

The social construction of "*target populations*" can have a *"powerful influence on public officials and shape both the policy agenda and the actual design of policy"* (Ingram & Schneider, 1993 pg 334). Political figures are often under immense pressure to provide policy which is advantageous to the more positively constructed target populations. These target populations have considerable (voting) power and control to get their issues

on legislative agendas while at the same time encourage the creation of more disciplinary and penalizing policy for negatively constructed target populations, ensuring they remain weak and suppressed (Ingram & Schneider, 1993, p. 334).

Stigma is therefore seen as something which is "*produced*" and used to maintain order within society. Most societies are able to maintain a level of conventionality by making distinctions between those who are "*normal*" and those who are considered to be "*different*" or "*deviant*" and thus societies produce this "*difference*" so they can maintain social control. The devaluing of certain people in society, while others are considered to be more superior, highlights the significance stigma plays in the construction of relationships of power and control. Power is used to legitimise inequalities of status and therefore operates not merely in relation to difference, as stressed by Goffman, but also in relation to social and structural inequalities and is part of a complicated battle for power (Aggleton & Parker, 2003).

It is important to remember however even populations without (perceived) power, will still engage in the construction of labels and stereotyping of individuals or groups of people within their communities, thus also engaging in the process of stigmatisation. But one might argue this is in fact a way of even the so called "weak", engaging in their own power games.

As stated at the beginning of this section, attempts to define or provide a definition of the concept of stigma is not an easy or straight forward task as there are so many variables. Another consideration is that much research done on stigma is done by those generally not affected by stigma but who work from a 'theoretical' point of view and so do not have a *real lived experience* of the people they are studying (Link & Phelan, 2001). In this sense, this research is quite unique.

3.3   Stigma and HIV and AIDS

HIV and AIDS related stigma has been recognised as a universal phenomenon, occurring in every country and region of the world according to UNAIDS (cited in C. Emlet, 2006). A phenomenon being a fact or occurrence which appears or is perceived, especially one of which the cause is in question (Fowler & Fowler, 1995).

HIV and AIDS carries with it such a stigma and so many prejudices it makes an HIV diagnoses unique (Elklit & Schmidt-Pedersen, 1998). Society has constructed metaphors around HIV and AIDS such as *the plague, death*, *punishment*, *sinful* or *evil* and *shameful* (Sontag, 2001) which has meant HIV (or AIDS) has emerged as a disease whose charge

of stigmatisation and whose capacity to create a spoiled identity is far greater than other diseases. Consequently, an HIV diagnoses is a traumatic event which requires continuous adjustment in regards to both physical and physiological losses (Gibson & Rohleder, 2006).

Those living with HIV often live with a fear of what *might* happen if others know they are HIV positive, but a more predominant fear is of what others might *think* of them (Fang, Lin, Naar-King, Stanton, & Yang, 2006). This 'perceived stigma' is often more profound than any 'experienced stigma' and ironically often precedes any form of 'experienced stigma' or discrimination.

Goffman's most significant writing about stigma was published in 1963 and was based primarily on research done on stigma in regards to mental illness, race or gender. While Goffman's conceptualisations can still be applied in many circumstances today and acknowledging Goffman was concerned about areas of social change and the social construction of individual realities, many who have used Goffman's framework especially in regards to HIV and AIDS, have interpreted it to be a static attitude rather than a continually changing social process which has critically limited the ways in which stigmatisation and discrimination have been handled in relation to HIV and AIDS. An example of this is when a person with HIV may be labeled by some as a deviant (homosexual, drug addict or sex-worker) who is being punished (through disease) for their sins, yet when we bring into the equation hemophiliacs and children who have contracted HIV, different social constructions are created as they (hemophiliacs and children) are seen as helpless (innocent) victims. However while the social construction around stigma may be somewhat different in these instances, discrimination, even against the helpless victims, may still occur (Aggleton & Parker, 2003). This is highlighted even at government and policy level when resources are needed for HIV prevention programmes but where funding is not put towards this as government officials do not want to spend money on 'powerless' groups such as those identified in Ingram & Schneider's "*targeted populations*" in figure 3 on page 12.

On a global scale women are the group most affected by HIV and stigma, particularly in Sub Sahara Africa where the ability to negotiate safe sex through condom use is difficult because of the subordinate role of women in society and cultural practices such as polygamy and female circumcision. Experiences of women living with HIV are intensified because they are commonly looked down upon as having "*departed from the socially prescribed behaviour worthy of good women*" (Gibson & Rohleder, 2006 pg 27) and are often seen to be blamed as the transmitter of HIV infection.

Although HIV prevalence amongst women in New Zealand is still relatively low there is increasing evidence which indicates New Zealand is following the international trend as numbers of women being diagnosed with HIV continues to increase. Living in a low prevalence country can in itself be isolating especially in a social and political climate which still perceives HIV to be a male disease. This has resulted in a greater feeling of stigmatisation by HIV positive women in New Zealand who feel acutely invisible in a male dominated environment and while not to the same extent as experienced by African women, many New Zealand women also feel subordinate as a result of their gender. The lack of HIV preventative messages aimed at women in New Zealand again highlights the invisibility and powerlessness of women and compounds feelings of stigmatisation (Bennett, 2007).

While there have been extensive international public education campaigns about HIV and AIDS there are still many people, even those working in the medical profession, who are still unclear about how HIV is transmitted and it is suspected that there is something more going on than a straightforward fear of infection as much of this fear seems to override logic. This was highlighted in an exercise undertaken by researchers at Arizona State University who asked several hundred business and science majors how they would feel about using cutlery a week or even a year after a person who had AIDS had used the implements. Even though the cutlery had been washed and even after a year and even though all who took part in the exercise were well informed about HIV infection and transmission, most of the people in the group acknowledged that they would feel some discomfort about using the cutlery. *"People do not want to touch people with AIDS or share their dishes even when they know they are being irrational"* said Carol Nemeroff who headed the study (cited in Gelman, 1993, p. 1).

An attitude study by psychologists Herek and Glunt (1993) found many people did not believe there was a negligible chance of contracting HIV through casual contact, even when this was being told to them by health professionals. People were more inclined to focus on what *possibility* of risk there *might be* than to the actual reality of the risk. Ironically this "*irrational fear*" around HIV transmission was not prompting greater care around safer sexual practices. What was being seen was an extreme overreaction to the *perceived* risks of casual contact and association with those who are HIV positive, with a serious under reaction to the *actual* risks (Gelman, 1993).

Stigma is considered to be one of the biggest barriers to HIV prevention and for the provision of care and support for people living with HIV or AIDS. When putting together strategies to control HIV, Klein et al. (2004) suggest that reducing stigma needs to be

one of the most important considerations. The fear of HIV stigmatisation and discrimination can lead to a delay in people coming forward for testing which could result in increased transmission of HIV as people continue to have unprotected sex (Chan & Reidpath, 2005). For those already living with HIV, the fear of stigma and discrimination has been known to stop them from accessing health services resulting in poor adherence to treatments and consequently increasing risks of drug resistance and disabilities (Heijnders & Van Der Meij, 2006).

There is a line of thinking which argues the stigma of living with HIV can be compounded or layered by other existing stigmas, for example, gay men or sex workers who are already associated with marginalized behaviours (Nyblade, 2006: Aggleton et al., 2002), are then doubly stigmatised if they also have HIV. Other examples of layered stigmatisation are indicated in figure 4.

Layers of Stigma
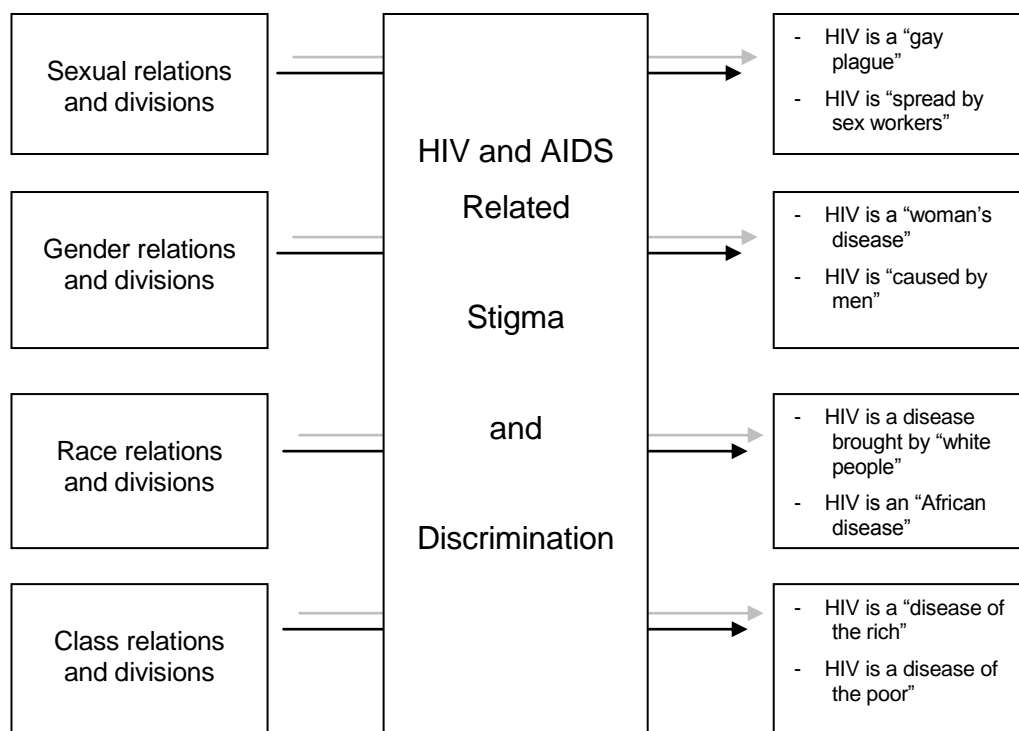
Figure 4: The link between HIV and AIDS and pre-existing stigmas
(Aggleton & Parker, 2002)

This layering becomes even more complex if people then fall within multiple categories of stigmatisation. For example a sex worker (1st layer of stigma) who is an intravenous drug

(ID) user (2nd layer of stigma) and is also HIV+ (3rd layer of stigma), is therefore living within three areas that are socially stigmatised, each overlapping, reinforcing each other and compounding both the external and internalisation of stigma (Chan & Reidpath, 2005). Stigma has been seen to be more extreme against already marginalized groups (targeted populations) such as these who are often held responsible for contracting HIV through their own (immoral) behaviours and are also often blamed for transmitting HIV to others (Deacon, 2006).

Interestingly the impact of stigma, appears to equally affect most sectors of these communities, i.e. gay men (Tugenberg, Ware, & Wyatt, 2006), African women (Gibson & Rohleder, 2006), African Americans and Caucasians (Ingram & Hutchinson, 1998).

Another outcome of HIV being associated to targeted groups and behaviours is that people who contract HIV are then assumed to be from these groups and may be stigmatised for being something they are not. For example a woman who contracts HIV may be perceived as being promiscuous or as a sex worker or injecting drug user thus layers of stigma are (incorrectly) associated to her (Aggleton & Parker, 2002).

Herek & Greene (1995) and Squire (2003) found regardless of the impact of HIV on a person's life, most people described an HIV diagnoses as 'life-shaping'[2] and while this affected many areas of their lives the two main areas of concern were around disclosure and relationships and both were inextricably linked with stigma. Secrecy and an attempt to keep HIV firmly separate from their everyday lives are seen as both enabling and constraining forms of protection for those living with HIV which require the need to develop appropriate coping strategies (cited in Barton et al., 2006).

3.4   Coping Strategies

The stigma attached to an HIV diagnosis abruptly displaces an HIV positive person from everyday social order and forces them into creating a substitute reality, so as to feel safe and to restore something of what has been lost. This includes things such as normalcy, authenticity and legitimacy (Persson & Richards, 2008). An HIV diagnosis robs a person from ever again feeling "*normal*" and while most people like to consider themselves as unique or individual, there is also an underlying need to be accepted by society, and also by oneself, as "*normal*" (Ingram & Hutchinson, 1999).

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[2] Life-shaping is thought of as something which drastically and irreversibly changes ones life.

The use of the word '*normal*' can be controversial in itself. After all what is normal? Just because someone has HIV does not mean they are not normal. Yet this is quite literally what lies at the core of stigma because in reality people who are stigmatised, for whatever reason, are generally not seen to be '*normal*'. Hence the term '*normal*' in the context of this paper has been purposely used to highlight this disconnect.

Goffman (1963) identified a sequence of three coping strategies often used by people living with or affected by stigma. He called these, '*passing*', '*covering*, and '*seeking the own and the wise*'. While much research has been done on stigma since 1963, more recent literature indicates these strategies are still commonly used by those whose lives are affected by stigma (Aggleton et al., 1998: Heijnders & Van der Meij, 2006: Hoffman, Murphy, & Roberts, 2002: Hutchinson & Ingram, 1999: Serovich, 2000).

3.4.1   Passing

The fear of the potential and irreversible repercussions of disclosing ones HIV status can be so strong, that for many, not telling anyone about their HIV status is the only means to "*normalcy*". Trying to *pass* (as normal) is seen as a way to make life go on as if nothing has changed, even though everything has. If diagnosed early, HIV is not physically apparent; there are no outward signs so it is easy to keep it a secret. By concealing ones HIV status and *passing* (as normal), a person is able to create a protective world, which is often easier for women who generally do not fit the perceived stereotype of someone who has HIV i.e. gay, sex worker or drug addict (Goffman, 1963; Persson & Richards, 2008). An extreme example of 'passing' in an HIV positive person would be having unprotected sex, passing or denying one's HIV status and potentially infecting others.

Passing is not a copying mechanism for people living with HIV alone. It is common practice for people who experience stigma for all sorts of reasons such as sexuality, gender, race or social status however it is not always possible to use passing in all circumstances. For example it is not so easy to pass as a different gender or if one is a different colour. In his book 'The Politics of Passing', Ginsberg (1996) discusses how during the days of slavery, being white was seen as a position of privilege and advantage by the black slaves and it was not uncommon for slaves of mixed race and of lighter skin colour to try to assimilate by passing as white (Ginsberg, 1996).

Another example is seen in Anderson & Holliday's (2004) study on passing in the lesbian community where women would often pass as heterosexual if they felt it would be to their disadvantage if it were known they were lesbian (Anderson & Holliday, 2004). Both of these examples highlight there is often perceived advantages to *passing.*

While Goffman (1963) believes *passing* could be unintentional, Kanuha (1997) suggests *passing* is a conscious, intentional process and the decision-making process involves a weighing up of costs and benefits (cited in Anderson & Holliday, 2004) as was the case of the slaves in Ginsberg book and for lesbians in Anderson & Holliday's study. For people living with HIV, disclosure is associated with possible high 'costs', such as rejection, exclusion, gossip, loss of privacy, loss of employment opportunities and being 'treated differently' (Anderson & Holliday, 2004) which again highlights that passing can be a conscious thought process.

HIV positive participants who took part in a study which explored "how experiences of disclosure and *passing* among heterosexuals living with HIV in Australia can be meaningfully conceptualised beyond therapeutic discourses and habitual metaphors", felt the perceived 'costs' and the fear of disclosure are not only influenced by fear of rejection and prejudice but also by a general feeling HIV is so foreign to heterosexual society, it was impossible for them to share they were living with HIV. They felt other heterosexuals were unprepared for HIV and lacked the necessary understanding to connect with such a life experience in a meaningful way (Persson & Richards, 2008) perpetuating the need to hide ones status and to pass (as normal).

While non-disclosure enables the appearance of a socially normative identity and facilitates the process of *passing*, providing protection and 'peace of mind' and gives people a sense of 'control' over their situation, however according to Eribon (2004), the strain produced as a result of leading such a duplicitous and dissociated life can often lead to withdrawal. Couples commonly tend to retreat into the protective space of their relationships where they feel safe, while single people often feel (and are) incredibly isolated and lonely (cited in Persson & Richards, 2008). While grasping at the illusion of 'normalcy' many find the constant strain of trying to manage their secret, challenging and draining. Metaphors commonly expressed to describe the effects of *passing* are, 'living a lie', 'living behind a glass wall', 'not being all there', 'not feeling real', 'living in a bubble', 'being deceptive' or 'inauthentic'. The constant lying and deceiving of those to whom they are close to can create an enormous strain which inevitably affects people's personalities and behaviours (Persson & Richards, 2008). Those affected will often not talk about HIV in any context and it is not uncommon for people to go to enormous lengths to ensure even family members never know (DeAlmeida, Kang, & Rapkin, 2006). This 'protective silence' is seen as one of the few ways to have some control over the possible stigma and discrimination one might face (Emlet, 2006).

Women in particular, often feel they are living a double life behind the façade of being a 'normal' person, mother or work colleague while at the same time trying to keep their HIV a secret and while this can take considerable effort, and involves a lot of lying, ironically being able to 'manage' the secret also provides a sense of accomplishment (Hutchinson & Ingram, 1998).

There is a conflicting train of thought which sees nondisclosure and *passing* as unconstructive and even dysfunctional. One study undertaken by Le'vy et al (1999) goes so far as to imply the unwillingness of some HIV-positive people to disclose, is a sign of their inability to adapt to their illness and attempts at *passing* is almost seen as a form of denial (cited in Persson & Richards, 2008). Regardless that there is significant literature and anecdotal evidence of the potential costs to a person living with HIV to disclose or be open about their HIV status, there is still a strong push by many health professionals, counsellors and social workers in America to encourage disclosure as they believe disclosure to be 'healthy' and even 'therapeutic' and many working in these fields are advised how to facilitate client disclosure (Serovich, 2000).

There is literature which supports the benefits of disclosure. Some people report how liberated and free they feel when they have disclosed, especially being free from the strains of needing to lie and make up stories in their attempts at *passing* (Pretter et al., 2005: Barton et al., 2006). However, care needs to be taken to ensure disclosure is not pursued as a blanket prescription as this may not be beneficial for everyone.

Emlet (2006) suggests that how people contract HIV can be an influencing factor around deciding whether or not to disclose one's HIV status. People who contract HIV through a blood transfusion for example are more often seen as the 'innocent' victims which has less stigma attached to it than contracting HIV from having unprotected sex as a result of a one night stand. The length of time a person has lived with HIV can also be a determining factor. Someone who is newly diagnosed and still heavily affected by the stigma of an HIV diagnosis will generally be less inclined to disclose their HIV status than someone who has lived with the disease for 20 years and who has had time to adjust with being HIV positive and is less fearful of negative repercussions (Emlet, 2006).

It has also been suggested people over the age of 50 are less inclined to disclose their HIV status as it is believed there is a greater possibility of moral judgment, stigma and discrimination from peers of this age group (Emlet, 2006). However it can be argued many of those now either reaching or in their 50's, are of the 'baby boomer' generation and while public attitude towards sex has been slow and even somewhat divided, this

generation is generally less sexually inhibited, being part of the 'flower power' and 'free love' generation and as a result developed new values and social norms and so are inclined to be more open minded and accepting (Pearson, Shirley, & Spoonley, 1994). This generation has also grown up with HIV and AIDS. Interestingly many studies done on stigma and discrimination in relation to sexually transmitted diseases, *excluded* those in their 50's as they were not perceived to be of the greatest risk group (Emlet, 2006). This is a dangerous assumption to make and may be an area which would benefit from more research as evidence has indicated there are a significant number of people in their 50's and 60's who contracted HIV after divorcing later in life and then entered back onto the dating scene (Pearson et al., 1994). [3]

As previously mentioned, those affected by stigma will evaluate the costs and benefits of disclosure. Often there are also other considerations such as the impact disclosure may have on children, family (especially elderly parents) and friends. For some, the process of passing is used as an attempt at erasing HIV from their social worlds at a more fundamental level. By compartmentalizing HIV and keeping it as something completely separate from their everyday awareness it is seen as the best (only) way of being able to get on with their lives and of managing depression. Those interviewed in the study done by Persson & Holliday (2008), felt being encouraged to disclose their status was actually 'a hindrance rather than a help', and highlighted the lack of understanding of the complexities of living with a stigmatised disease such as HIV by the professionals concerned. While they accepted by not disclosing and attempting to *pass* as normal, they helped to perpetuate stereotypes and society's ignorance of heterosexual people with HIV, however they commented they were the ones who would have to live with the consequences and most were not prepared to take that risk (Persson & Richards, 2008).

3.4.2 Covering

As HIV progresses people may become ill or need to start medications which can cause external and visible side-effects and it can become increasingly more difficult to use *passing* as a coping strategy. It is at this stage another strategy called '*covering*' may be used. The façade of being 'normal' is dropped to some extent but attempts are still made to conceal the *true nature* or origin of the illness. While there was a degree of deception required during the *passing* phase, the *covering* phase involves a lot more lying, story-telling and deceit. During the *passing* phase there would generally not be any visible symptoms so secrecy and silence would have been more predominant than actually

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[3] There is also statistical data which suggests the Baby Boomers aged 50+ are also at risk of contracting other STI's when they re-enter the dating scene as they no longer use protection for contraception purposes.

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lying. During the *covering* phase, fictitious ailments and excuses are created to '*cover'* the reality of what is truly happening. There is considerable guilt as well as moral and ethical dilemmas because of the need to lie yet it is justified, because the truth is seen as a threat to survival (Goffman, 1963).

Women living with HIV who have children often find caring for their children is one of the main reasons to continue living and will generally try to maintain as normal an environment as possible for the sake of their children (Abell, Kamata, & Ryan, 2006), but it is often around the '*covering*; stage children start to ask questions as they may be able to see things are not right. Another dilemma occurs, to tell the children or to continue to lie? Those who do tell their children often request the children maintain the secret and then feel guilty at putting this burden of secrecy onto their children. One American study found 77% of the mothers instructed their children not to tell other people while 23% of the mothers did not give their children any instructions either way and found that the children instinctively where inclined not to disclose their mothers HIV status. It was felt this was probably more to do with the children trying to protect their mothers from possible harm than worrying about the impact on themselves, however a small number of children were concerned their friends might gossip and not want to be friends with them if they knew (Hoffman, Murphy, & Roberts, 2002).

Some women choose not to tell their children as they wanted them to have as '*normal'* a childhood as possible without the fear of exposing them to possible prejudice or living with the worry their mother might die. The decision to disclose or not also often needs to be outweighed by the concern that the children might figure things out for themselves as they increasingly become aware something is wrong with their mother (Hoffman et al., 2002: Barton et al., 2006) which makes the process of *covering* all the more important.

While *covering* effectively is an extension of *passing* the main difference at the covering stage is that illness, or the fact something is wrong, is not so easy to be kept hidden and the fear others might 'guess' what is wrong adds an extra level of anxiety.

3.4.3   Seeking the own and the wise

Disclosure of one's HIV status is considered to be largely determined by the need for support and the need to confide in someone as the burden of the 'secret' of living with HIV becomes too great. This stage can be very confronting and initial disclosure might involve only disclosing to immediate family members such as one's mother, father or siblings or to carefully selected close friends in an attempt to find sympathetic others who will be accepting of their situation. Some may choose or feel the need to connect with

others like themselves who share the stigma. This might involve joining a support group or just connecting with others who are living with HIV as there would be a level of acceptance and an opportunity for sharing information and providing support. The need to discuss their situation to health professionals and sexual partners are also determining factors in disclosing one's HIV status. This strategy is called 's*eeking the own and the wise'*, the '*own'* being others like themselves living with HIV who share the stigma and the '*wise'* referring to health professionals and therapists as these people are seen as safe (Goffman, 1963).

Interestingly, many women choose not to seek support groups as they have their own preconceived perceptions on what sort of person contracts HIV and often feel they don't belong in such a group. Many also do not want to be seen to be associated with HIV support groups for fear their HIV status might somehow be discovered through association (Hutchinson & Ingram, 1998).

In a study done in Australia of men and women living heterosexually with HIV, Barton et al., (2006), found many heterosexuals living with HIV did not have a sense of shared identity or community with others living with HIV and most had little or no contact with other HIV positive people. While HIV positive people felt the peer support network was significant and those who had accessed it found it to be hugely beneficial especially in being able to share experiences with others in a similar situation, many however did not continue to use the services on a regular basis. A number of reasons were given: the lack of resources and lack of capacity to facilitate everyday peer contact and community building was a predominant factor. Geographical distance, family commitments, transport and work commitments were also other common factors but it was a lack of wanting to identify as an HIV positive person which was the most significant stumbling block. There appeared to be a distancing by people who felt others who were HIV positive where not (normal) like themselves. This distancing was seen as an example of the diversity of those living with HIV (Barton et al., 2006). Yet research has shown that a connection with people in similar situations helps those living with HIV to reduce feelings of isolation and stigma. Self-help and peer support groups such as Positive Women Inc., have been reported to play an important part in formulating a person's identity and self-esteem, their coping skills and social interactions (Heijnders & Van Der Meij, 2006).

The *perception* of social support is believed to be more important than the *actual* social support for the mental health and well being of women living with HIV. And while women generally *perceive* friends to be more supportive than family, as friendships are generally sought and maintained because they are mutually enjoyable, family support is

considered to be more significant, probably because of the emotional bonds of family relationships (Goodry, Huang, Montoya, & Simoni, 2005: Kimberly, Lewis, Mosack, & Serovich, 2001).

Barton et al., (2006) in their study on heterosexual men and women living with HIV, found that while many women disclosed their HIV status to their mother and/or close sibling/s often the extended family were not told as there was still significant fear about being rejected. There was also a concern others might not be able to cope with the information and especially if the HIV positive person was well, there did not seem to be any reason (benefit) to tell. The most common reason for women not wanting to disclose to family and close friends however was because they did not want to worry loved ones with the information and did not want to burden them with the need to 'keep the secret'. It was also noticed that when telling someone about their HIV status, the person being told would often require support and it was more than likely they would tell someone else. While it was understood this occurred because the person being told needed support, it was however a significant consideration when choosing who to disclose one's HIV status to.

The study found when people did disclose they were often surprised friends, family members and potential partners, were usually much more accepting and supportive than they had expected. Disclosure to family or friends however did not always result in support, as they (family and friends) often did not know how to react and would be hesitant to talk about HIV. Some found this liberating while others were confused as they were unsure what this meant and interpreted it to be because there was an unease or disinterest by their family or friends in their situation (Barton et al., 2006).

While most working in the medical profession are compassionate, supportive and operate in a professional manner, there is still a significant mistrust of health professionals and many women will only disclose to health professional out of necessity. While the fear of the *perception* of discrimination is far greater than the reality, discrimination does still exist (Aggleton & Parker, 2002) and one of the areas this happens most frequently is when interacting with health professionals (the supposed "*wise*"). The most common forms of discrimination by health professionals are around breaches of confidentiality, stereotyping (you must be a drug addict, sex worker, or sexually promiscuous), being treated differently or even being refused to be treated at all and often being treated as a curiosity or a novelty (Barton et al., 2006).

In an American article on HIV positive mothers and stigma, a common concern in regards to health professionals (the wise) was that women,

> feared being discredited as mothers and spoke of feeling offended by assumptions made by their health care providers that they should cease to reproduce, have abortions, or be sterilized (Hutchinson & Ingram, 1999, p. 101).

Despite the potential advantages of support it appears '*seeking the own and the wise'* possesses significant contradictions between a preference for secrecy and the desire to disclose. This is understandable as it is at the point of disclosure that there is a loss of control, either real or perceived, by the stigmatised person as they are unable to predict or control how others will react. Keeping the secret, through passing and covering, at least allows for the illusion of control and avoidance of discrimination.

3.5 Discrimination

The words stigma and discrimination are often used together and while they do mean different things, discrimination is in fact the *enactment* of stigma, the end result of stigmatisation. That is, the outwardly seen behaviours such as verbal and physical abuse and social distancing which includes withdrawing from people who are HIV positive often from a fear transmission of the disease can be through casual contact, or from being morally associated with someone who is HIV positive (Nyblade, 2006).

HIV related stigma is commonly seen in the form of discrimination at a societal level as it is at that level it can become "*normalized*" through the implementation of rules and laws and in the form of government policies and targeted populations (Link & Phelan, 2001 and Ingram & Schneider, 1993). This may include HIV related legislation which can contain measures ranging from travel and immigration restrictions for people living with HIV to forced declaration of HIV status on job and/or course application forms and can also result in exclusion of people with HIV from certain professions. Discrimination by health care workers towards people living with HIV is also widely reported, these involve refusal to treat people with HIV, judgmental attitudes and breaches of confidentiality (Aggleton et al., 1998).

This was highlighted in a New Zealand paper on women and HIV (A feminist perspective) where women felt they were more stigmatised by health care workers than their male counterparts. Women stated how while healthcare professionals possibly had the medical knowledge about HIV, they lacked insight to '*their own personal values and prejudices*' (Bennett, 2007, p. 8), resulting in the women feeling they were being judged

and not being taken seriously leaving them feeling totally vulnerable and unsupported (Bennett, 2007).

A recent update on information about government policies towards HIV and AIDS, highlighted a significant disparity between declared national policies and their reported practice in many countries (Aggleton et al., 1998). This is also relevant in New Zealand. An example of this is when in 2005 the New Zealand Immigration Department introduced legislation requiring compulsory testing for HIV of all new migrants to New Zealand and those found to be HIV positive are generally refused entry in the first instance. Insurance policies, many job application forms and even some course application forms ask if people have HIV. In most cases there is no relevant reason for this line of questioning. While there is legislation in place in New Zealand to protect the rights of those living with HIV[4], these avenues are often so drawn out and require more 'outing' of one's status, that most do not follow through with the process.

HIV and AIDS related stigma and discrimination is a result of fear from contracting a life threatening disease for which there is no cure and together with the metaphors constructed by society which suggest HIV is a disease which affects those ('others') who are of loose or deviant moral values and/or behaviours has resulted in the stigmatisation and discrimination of marginalized sectors of society.

> Discrimination then operates though internalised stigma by encouraging stigmatised people to believe that they should not enjoy full and equal participation in life, be it social, economic, sexual or otherwise (cited in Barton et al, p. 15: Link & Phelan, 2001, p. 380).

3.6 Internalised stigma

When the concepts of stigma, which are initially conceptualised externally by society, are accepted and turned inwards by the stigmatised person this results in what is called the 'internalization of stigma' or 'self-stigma'. This requires a level of acceptance by the stigmatised person that what is being said by society is true. This is then experienced in the form of negative self image or negative self-worth which may include feelings such as shame, guilt, being unclean and that one is a bad person. These being the exact concepts projected by society, and can result in the implementation of coping strategies[5] and behaviours of self isolation and withdrawal (Nyblade, 2006).

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[4] Human Rights Act 1993 & Privacy Act 1993

[5] Further discussion of copying strategies are provided in chapter 4.4

Crossley (2000) suggests it is through the use of language one's own identity is constructed. So for a person living with HIV, metaphors and stereotypes used to describe HIV as being 'evil', 'dirty', 'sinful' and 'deviant', are thus incorporated into a person's interpretation of their own self-identity. It is through this internalisation of stigma that Goffman's concept of a '*spoiled identity*' is created and the HIV positive person becomes bound to this identify which manifests deep rooted feelings of shame and being bad or dirty and contaminated.

In contrast to this, Hollway & Jefferson (2000) argue, people's identities are not passively created through language. They suggest when the 'self' is attacked or threatened a person is capable of creating 'defenses' against the threat/s and they become "*active emotional participants in their experience*" (cited in Gibson & Rohleder, 2006, p. 29). So while a person may internalise stigmatising views of themselves, they can be actively involved in managing their identity and protecting themselves against the uncertainties associated with a '*spoiled identity*' (cited in Gibson & Rohleder, 2006).

It would appear the way a person internalises stigma is not straight forward and how a person's personal and emotional experiences interrelate with their social experiences is more of a determining factor in the process of identity construction.

A study by Gibson and Rohleder (2006) done in South Africa, where black women are generally situated at the lowest level on the social, economic and political power hierarchy[6], these women were also found to be the group most affected by HIV. In some communities women were regarded as dirty and diseased as they were seen to be the source and transmitters of HIV. These social constructs of stigma are so profound that once a woman is diagnosed as being HIV positive she instinctively incorporates the negative constructions of HIV related stigma into her own sense of self worth, internalising the perception of herself as being dirty, dangerous and contagious and as a person '*who is a danger to society*' (Gibson & Rohleder, 2006 pg 34). One woman felt this to such an extent she was no longer able to contemplate having sex with her partner as she feared, "if I have sex with him, all the dirty things that came from me can make him very sick" (Gibson & Rohleder, 2006, p. 34).

An interesting finding in this study was how these women tried to protect themselves from the impact of internalised stigma by using a process called "*splitting*". This splitting was of the self in the past when they were sick but did not yet know or had not yet been

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[6] As outlined in Ingram & Schneider's (1993) graph on 'Constructions and Political Power: Types of Target Populations'

diagnosed as being HIV positive, to the present self, which was now healthy (normal) because they were on medications. This helped them to remove themselves not only from the fear of illness and death but also from the physical symptoms of HIV which inevitably resulted in stigmatisation. So here we can see an example of women being actively involved in creating a defense against their 'spoiled identity' by trying to build a positive identify for themselves, however it was noticed the women often struggled to maintain this (Gibson & Rohleder, 2006).

The often insurmountable feelings of fear, shame, guilt and embarrassment leave some women so unhappy to the extent they result in self imposed social isolation and consequential loneliness which can lead to depression (Emlet, 2006). Rates of depression among HIV positive people have been said to be twice as high as the general population with rates of depressive disorders estimated to be between 4-14%. This is seen even more so amongst women where studies have shown clinical anxiety and depression ranges from 30-40% and rates of post traumatic stress disorder are being reported to be as high as 62% (Kimberly et al., 2001). For many women the fear of HIV related stigma is of more concern than the fear of dying (Abel, 2007).

A study done by Calabrese and Corrigan (2005) on assessing and diminishing self-stigma within mental illness and depression found cognitive therapy, a carefully planned approach where people are encouraged to recognize and adjust negative beliefs and interpretations, was an effective strategy in helping them to overcome the affects of self-stigma. This cognitive therapy included education around identifying stigmatising symptoms by exposure to symptoms and situations to help in the desensitization of their fears. Cognitive therapy was found to increase self-esteem in patients who had schizophrenia as well as helping to improve their functioning in social situations. But although this study indicated some positive results, Link, Mirotznik, & Cullen (1991) felt this type of copying strategy had more negative than positive outcomes as they argue stigma is so ingrained through society and culture, its effects cannot be overcome through coping strategies by individuals alone (Heijnders & Van Der Meij, 2006).

Both the external and the internalisation of stigma ultimately affects all aspects of a person's life and where the cause of the stigma is through a sexually transmitted disease such as HIV it can have a detrimental effect on one's sexuality and also in negotiating relationships.

3.7   Relationships and sex

Testing HIV positive is often linked to a loss of sexuality. Research has identified that penetrative sex is considered '*normative*' for heterosexuals yet strong barriers to condom use continue, particularly from men. With HIV being a sexually transmitted disease, for many women their sexual identity becomes interwoven with feelings of guilt about being contagious or being dangerous and internalised feelings of shame and being undesirable often result in a great sense of loss as some (single) women feel they will never again be able to have another relationship (Gibson & Rohleder, 2006: Barton et al., 2006).

The fear of rejection and being undesirable as well as an (often unrealistic) perception of being hugely infectious together with the fear of possibly transmitting the virus, cause (self imposed) barriers for many women when contemplating relationships.

A study undertaken in New Your by Lekas, Schrimshaw, and Siegel (2006), on 'Diminished sexual activity, interest, and feelings of attractiveness among HIV positive women', found an HIV diagnoses dramatically affected many of the women who took part in the study. While there were a number of reasons for this the predominant concern was around the fear of transmitting HIV to their partner. Also the planning required to engage in 'safer sexual practices' took away any spontaneity around sex and even when protection was used, women still worried the condom would break. This anxiety and worry diminished any pleasure or enjoyment of sex and consequently, as seen in the study by Gibson & Rohleder (2006), and Barton et al. (2006), many women consciously chose not to bother with sexual relationships. While a few women were relieved at no longer needing to worry about sexual relationships, most however felt saddened at no longer feeling sexually attractive and at the loss of their sexual freedom (Lekas, Schrimshaw, & Siegel, 2006).

The fear of disclosing ones status to a new sexual partner is for many women absolutely terrifying as they are faced not only with the fear of rejection but also often needing to deal with the emotional reactions of the person they are telling. Combined with this is the need to trust and have faith that the potential partner will not then disclose their HIV status to others. The issue around 'when to tell' can also be fraught. Does one tell straight away or wait for a level of intimacy and trust to develop? If one waits, the partner may become angry because they were not told earlier, especially if sex has already occurred, the partner might feel deceived or betrayed. If rejection where to happen after a level of intimacy had developed, the pain of rejection would be much stronger than had it occurred at the beginning (Barton et al., 2006).

For women already in relationships, especially where the partner is negative, concerns about the risks of transmitting HIV and about partners leaving them when they became ill or the thought of their partner having to take care of them while ill is difficult for women to come to terms with and low self esteem is common. These feelings of low self esteem can result in women accepting 'unacceptable' behaviours from their partners (Fang et al., 2006), and it is not uncommon for women to remain in (existing) relationships, which are not healthy or happy, because of the fear that "no one else would want them" (Barton et al., 2006).

Yet, despite the anxiety around disclosing to a potential partner, overall women are generally quite optimistic and active around relationships (more so than HIV positive men), with many developing loving and supportive relationships after their diagnoses (Barton et al., 2006)

In light of these studies it is evident interventions are needed to address not only the issues around women's sexuality but in regards to HIV stigma and discrimination overall.

3.8   Actions and Interventions

Aggleton and Parker (2002) suggest there needs to be a move away from the current thinking that stigma is a static individual attribute towards a more conceptual structure which is based on an understanding that stigma (and discrimination) are social processes and thus can be opposed and contested by social action. New approaches to research are needed which take into consideration social, political, economic and cultural influences (Aggleton & Parker, 2002: Link & Phelan, 2001: Ingram & Schneider 1993).

Heijnders & Van Der Meij (2006) suggest interventions for those affected by both internal and external stigma due to HIV, need to be multi-targeted and orientated at multi-levels. A combination of counseling, education and contact (between the public and those affected by stigma) are needed and interventions at the government level need to support efforts to create a shift in the power relations that remain and allow stigma to continue (Heijnders & Van Der Meij, 2006). However Aggleton and Parker (2002) caution care needs to be taken in the implementation of programmes as they may unconsciously increase HIV stigma (and discrimination) because they may bring attention to the division between the 'general population' and the 'high risk' population. They go on to say that lessons should be learnt from the experience of community organisations affected by stigma and discrimination and that these communities be empowered and encouraged to lobby for changes in laws and polices (Aggleton & Parker, 2002).

Many of the gains made in reducing stigma and discrimination have in fact come from work within and by the communities most affected. The increasing use of people living with HIV or AIDS as educators, is proving to be a useful strategy in prevention. As well as raising awareness, open discussion of HIV also helps to create an environment of acceptance and support (Aggleton et al., 1998). However, interventions should not be the sole responsibility of the communities most affected.

3.9   Summary

Defining or conceptualizing stigma is not a straightforward academic exercise. There are many facets to stigma; that of the individual, society and also through the beliefs of the stigmatised persons own viewpoint and behaviours. However it is evident that thinking around HIV related stigma (and discrimination) continues to focus on the 'individual'. It is still predominantly perceived as what one individual does to another or what happens to an individual through their own life (deviant) choices, i.e being gay, a sex worker or sexually promiscuous. What this review highlights is that what is often being ignored or forgotten are the social processes which are also involved as identified by Link and Phelan (2001) and Ingram and Schneider (1993).

Peter Piot, the Executive Director of UNAIDS said in 2000, "combating stigma is one of the five most pressing items for the world community" (cited in Maughan-Brown, 2006). The stigma implicit in HIV and AIDS and its many prejudices make an HIV diagnoses unique. The stigmatisation and capacity to create a spoiled identity is far greater than any other disease, which reinforces the statement made by Peter Piot in 2000, that it is still one of the most pressing items for the world community.

While globally women are the most affected by HIV and stigma, yet in New Zealand HIV is still very much perceived as a 'mans disease'. Perceptions such as these continue to isolate women in New Zealand and perpetuate the need for coping strategies identified by Goffman (1963) such as passing and covering.

Feelings of being less sexually appealing hinder women's ability to engage in sexual relationships while perceptions of HIV stigma and discrimination continue to perpetuate the internalisatoin of stigma as well as self discrimination.

It is evident from the literature review that interventions and actions need to be taken and it is hoped this research, which is a project initiated by, and for, women living with HIV in New Zealand, will be a significant step.

4 Methodology

4.1 Introduction

This chapter will discuss the holistic approach of co-operative inquiry as a research method and will describe the theoretical stages and cycles of co-operative inquiry as well as the practical applications of the inquiry as they applied to this project.

Link and Phelan (2001) identified that generally research on stigma is done by those not affected and consequently much research on stigma is from a theoretical point of view involving researchers who have no real lived experience of the people they are studying. With this in mind, and considering in this case the researcher was also a woman living with HIV, the method selected for this project was that of co-operative inquiry as it made provision for the researcher to be able to participate in the inquiry as a co-participant and enabled the research to be done from a 'real lived experience'.

Co-operative inquiry involves a process which has participants undertake mutually decided actions as part of the development of the inquiry which in itself is a form of intervention. This process can be hugely empowering for those who are affected by stigma (Aggleton et al., 1998).

Central sources of information on co-operative inquiry include, 'Co-operative Inquiry; Research into the human condition' by John Heron and 'Collaborative inquiry in practice' by John Bray, Joyce Lee, Linda Smith and Lyle Yorks (Bray, Lee, Smith, & Yorks, 2000), which were both significant resources used in the design and implementation of this project.

Also discussed in this chapter is the process used to recruit participants for the project and includes some general demographic information about each of the participants.

Methods of data collection and recording will be explained and finally a review of the ethical considerations undertaken in preparation for this theses are discussed.

4.2   Co-operative Inquiry

Cooperative inquiry is an open process; it is about discovery and learning, not about confirming or validating previous theories or hypothesis. It is about making meaning or making sense of experimental data which involves interpretation, reflection and contemplation (Bray et al., 2000)

Much research is validated on *propositional knowledge* which has a bias towards intellectual knowledge with the researcher as the expert, based on rules of logic and evidence. Heron (1996) believes a more holistic approach to research is required and co-operative inquiry is based on an interdependence between propositional knowledge and *practical knowledge* which is about knowing how to do a skill; *presentational knowledge* which is about intuitive grasping of patterns through graphics, movement, verbal and other art forms; and *experiential knowledge* which is about actually meeting and feeling the presence of people, places, energies or processes. Heron expands on this by arguing these four types of knowledge make up a systemic whole based on a pyramid of up-hierarchy where what is below supports and empowers that which is above and where experiential knowing, the real lived being-in-the-world, is the base of this pyramid as indicated in figure 5 (Heron, 1996).
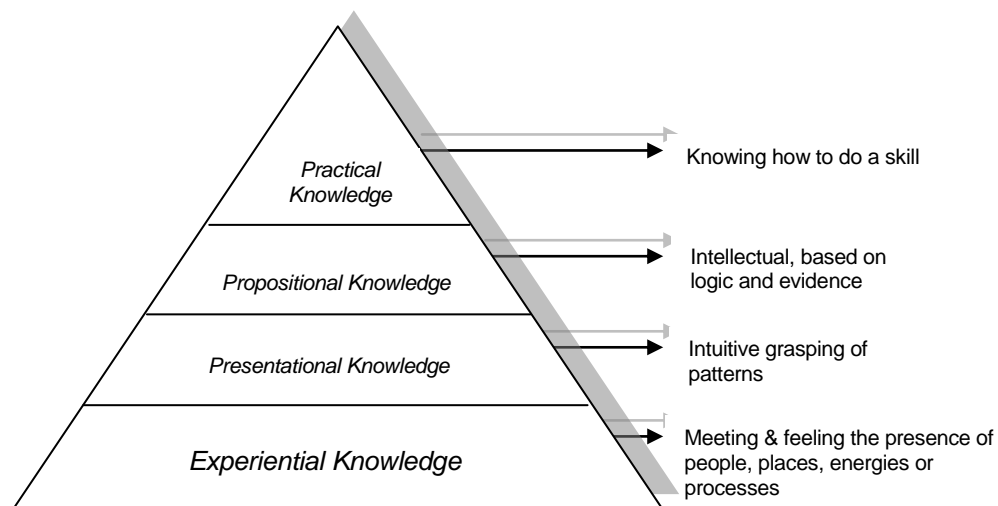
Figure 5: Pyramid of fourfold knowing
(Heron, 1996)

The type of up-hierarchy outlined in figure 5 is in stark contrast to the classical down-hierarchy where generally the intellectual (the researcher) is at the top and controls everything without really being involved. In this regard, co-operative inquiry is not about research 'on' people but rather a form of research 'with' people requiring the process be

co-initiated with all participants playing equal parts (Bray et al., 2000). So while I was the researcher in this project, using co-operative inquiry as a methodology enabled me to be that of a co-subject and to become a participant in the project.

Being a participatory, action-based inquiry method, co-operative inquiry provided the participants, in this instance, women living with HIV, the opportunity to discuss their thoughts and lived experiences on stigma and of living with HIV. While there are some similarities between co-operative inquiry and action research, which also goes through repeated cycles of planning, observing, reflecting and re-planning and involves a degree of collaboration and participation, there are however some very significant differences. Action research generally has a clearer focus on problem-solving and is commonly carried out amongst professionals in organisational structures. It is generally not involved in the investigation of the human condition as it does not consider the full range of human sensibilities as a means of research (Heron, 1996). Co-operative inquiry, through its process of sharing experiences (experiential knowledge), reflection and further discussion, encourages participants to learn to interpret meaning and gain a better understanding of their world and through the process of agreed actions can include personal transformation (Bray et al., 2000).

Co-operative inquiry also has a significant relationship with qualitative research. Qualitative research focuses on discovery, description and meaning rather than the more quantitative approach of prediction, control and measurement of which there are numerous limitations especially when attempting to apply this method to human issues and experiences (Laverty, 2003). Qualitative research is not so much a study about something which represents the population but more about a detailed study on the social lives of small groups. It involves asking people how they feel about something and what it means to them (Davidson & Tolich, 1999), which aligns significantly with co-operative inquiry.

The difference however is that qualitative research as a social science, is more about people *being* studied, often in their own social settings through negotiations with the researcher, but still managed and analysed by the researcher and there is no participation in the experience by the researcher. Co-operative inquiry on the other hand is a wide ranging science about any aspect of the human condition and involves doing research *with* people. Participants, including the researcher, work together, collaboratively and are fully involved, exploring together through their own experiences in all aspects of the research project (Heron, 1996).

Co-operative inquiry is based on *inductive logic* where the researcher will generally move from observation and seeking patterns to the theory as opposed to *deductive logic*, which is commonly quantitative and starts by generating a hypotheses based on theory and then moves to prove or disprove the hypotheses (Davidson & Tolich, 1999).

The process of inductive logic often begins with a strong personal interest in a specific topic, as was the case for me. In my work as National Coordinator for Positive Women Inc., I found I was often having discussions with women who told me they felt ashamed and were fearful of people knowing they were living with HIV. I also understood these fears from a personal perspective. I was curious as to why women living with HIV felt like this and what was underlying these fears and I was keen to investigate this further.

4.3   Theoretical stages of co-operative inquiry

The theoretical process of a cooperative inquiry involves four stages which together make up the cycle from reflection to action to reflection. These cycles are then repeated.

4.3.1   First Stage

The first stage of the co-operative inquiry was the first reflection stage, it was about choosing a topic of inquiry and required the consideration of an opening statement to launch the inquiry. Preparing a plan of action such as how long the action phase would last before the next reflection phase, how many cycles of reflection and action, the time frame for the inquiry, deciding on methods of recording and when they were to be done.

This was an *internally initiated* inquiry. This means the initiator (myself), was internal to the focus of the inquiry making it possible to be personally engaged and to have an understanding of the culture and practices of the research. It also meant I was able to fully participate as a co-subject. No matter how empathetic, well read or well intentioned a researcher may be, only a person who lives with HIV can truly understand what it is like. That the researcher in this project was also a woman living with HIV was a significant factor in cultivating a sense of trust and intimacy amongst the participants. It enabled a significant level of understanding and interpretation of the discussions due to a 'real shared' perspective (Heron, 1996) and not just a theoretical point of view (Link & Phelan, 2001).

The length of time for each action phase can depend on the focus of the inquiry or may be restricted by a time constraint, which was the case for this inquiry. It was therefore important to decide earlier on in the inquiry how this would work, although provisions

should always be open for review. Because this was an internally initiated inquiry being done as part of a thesis, I chose the topic of inquiry and recommended the methods of recording and suggested a time frame of 4-5 action and reflection cycles[7]. In a true co-operative inquiry these would be decided collaboratively by all the participants. As none of the participants had any prior knowledge of the process of co-operative inquiry, they agreed to start the inquiry using the recommendations I had suggested with the understanding the process was able to be reviewed at anytime. Even with considerable time constraints, this project was still able to complete 4 cycles of action and reflection.

There are two possible outcomes when engaging in a co-operative inquiry. If the inquiry process is to be of an *informative* nature, the outcomes are more inclined to be propositional and presentational, in the form of written reports. If the outcomes desired are to be of a *transformative* nature, participants focus more on forms of practice and experience, which was the case in this inquiry.

Because of the involvement of two external participants[8] this was not a *full* form of co-operative inquiry in the true sense. A *full* form of co-operative inquiry is when all those involved, including the researcher, work together as co-subjects. Even though the roles of the two external participants were in a support capacity and not as researchers, to be precise this was a *partial* form of co-operative inquiry because neither of them were people living with HIV. They did not participate in the actions so were unable to fully participate during the discussion and reflection stages so were not involved in the *experience* of the inquiry.

Heron (1996) suggests determining the culture of an inquiry is important and refers to these as either *Apollonian* or *Dionysian*. An *Apollonian* culture has a more rational, systematic, controlling approach between reflection and action and will generally result in each reflection phase being used to think about the last action phase which is then used to decide on the next action. A *Dionysian* culture will generally take on a more, expressive, creative and spontaneous approach and actions will evolve as a response to a situation. These are two distinct and quite different cultures, however a combination of the two can also work (Heron, 1996).

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[7] Heron (1969) recommends 3 as the minimum (for the total) number of inquiry cycles of reflection and action and that between 5 and 8 full cycles of reflection and action provides enough room for useful outcomes without being too demanding on both time and motivation (Heron, 1996).

[8] This is discussed in more detail in chapter 5.5 and 5.6

While the participants in this inquiry did not use language such as *Apollonian* or *Dionysian* to define the culture of the inquiry the group did however instinctively develop a culture. Some of this was as a result of guidance initially by myself, in the beginning stages of the inquiry, but it mostly seemed to evolve as a natural process.

Initially I had envisaged a more *Apollonian* cultural approach to the cycling between reflection and action. However, the changes made by the participants as the inquiry progressed, highlighted the fluid, flexible and collaborative process of co-operative inquiry and as a result the culture fluctuated between *Apollonian* and *Dionysian* over the period of the inquiry, which highlighted a combination of the two can work.

Another consideration at this stage was to decide if the action phases were to occur *inside* or *outside* of the confines of the inquiry and whether or not the inquiry was to be an *open* or *closed boundary* process.

Outside action phases are when participants decide to carry out their actions independently (or in pairs or small groups), but the actions occur outside of the group, when they are not together, generally in-between inquiry sessions. These are then shared, discussed and reflected on when the group comes together. An *inside* action phase is when the group stays together in the same space during their action phases working on the actions together, in groups or even individually, but within the confines of the inquiry session.

A *closed boundary* inquiry process is when only inquiry participants are involved in the action phases which would often be the case in an *inside* inquiry. An *open boundary* inquiry would be when action phases are done *outside* of the group where participants engage with other people outside of the inquiry as part of gathering information or communications during their action phase, although an *inside* inquiry could invite a guest speaker as an action which would then make it an *open boundary* inquiry, so there are no hard and fast rules.

The women in this inquiry chose to engage in an *outside* inquiry process as they decided the actions would be undertaken during the week in-between each of the inquiry sessions. As the women would be interacting with people *outside* of the inquiry group to gather the information, this was then an *open boundary* inquiry.

It was also necessary for the participants to consider if they would each investigate different things during their action phases or if they would all investigate the same thing. If participants decided to each investigate something different, this is called *divergent*

(each participant diverges and does something different). If the group decides to investigate (or do) the same thing, this would be called *convergent* (converging, working together). Another aspect to consider was if what each person was doing would represent only *part* of the topic, subsections which together make up a whole, or the *whole* of it.

For this project the participants chose a *divergent* process with each working on their own actions however these individual actions were sub parts of a greater whole

The final thing to be considered at this stage was how participants intended to record the data they would gather during their action phases so they could then present this data to the group at the next reflection stage. This is discussed in more detail in chapter 5.5.

4.3.2   Second Stage

The second stage of co-operative inquiry is about the first action phase when the participants are exploring in experience and action, were a range of inquiry skills were being applied and involve the recording of the data.

As participants in this project had decided on an *outside* inquiry this meant each of the women undertook an agreed action, during the days in-between each of the inquiry sessions to collect the relevant data. This data was recorded and then shared with the rest of the group at the next inquiry session for discussion and reflection.

4.3.3   Third Stage

The third stage requires participants to be in a state of mind that is fully immersed in the second stage, exploring in experience and action, and being fully open to the experience and practice of the inquiry.

Heron (1996) defines this stage as 'the bedrock', the "*touchstone of the inquiry process*" (Heron, 1996 pg 84). At this stage participants will be investigating, enquiring and experiencing and through this process hopefully gaining new insights or gaining unexpected personal and social growth. While this phase can lead to new awareness alternatively it can also result in distraction or inattention particularly in an *outside* inquiry, such as this, when participants are working on their own and when everyday life can intrude and distract, preventing participants from being involved. Whereas with an inside inquiry it can be easier to remain focused and enthusiastic as there are other participants to encourage and support each other making it easier for everyone to stay motivated and engaged.

4.3.4   Fourth Stage

The fourth stage of co-operative inquiry was the reflective stage. This was when participants got together to discuss, reflect and tried to make sense of their experiences.

The participants did this by sharing the data they collected during their action phase with each other. The way this is done can depend on how the group decides to share and can involve verbal or visual presentations which might also include things such as music, dance or storytelling. For this inquiry the women chose to verbally relay their actions and some presented visual resources which they had collected.

Once each of the women had shared, their information this was collated and involved searching for similarities, themes, patterns and even differences and then trying to make sense of it all. This sense making was hugely *transformative* for the participants, and involved changes in behaviours, attitudes and even skills .This transformation process was one of the key outcomes desired from the co-operative inquiry process.

Having made sense of the first action phase, the participants then reviewed the process of the inquiry and decided on the next action phase. During this reflection stage the group may decide to make changes to the process as a result of lessons learnt from the first action-reflection phase or even try something different (Heron, 1996), which occurred during the process of this inquiry.

After stage four, the inquiry was then launched into a series of repeated cycles of stages 2, 3 and 4.

Deciding when an inquiry should end may not always be clear in the beginning stages unless strict parameters are set from the start, which was the case in this inquiry as the inquiry had a predetermined time constraint. The end of an inquiry must do so with a final reflection phase. This helps to pull everything together and to clarify the outcomes of the inquiry and how to make the best use of the outcomes. In the case of an *Apollonian* culture this might involve the writing of a report, whereas an inquiry which has adopted a *Dionysian* culture this might be in the form of new practices or personal transformations which can extend into social and environmental transformation.

While this inquiry fluctuated between *Apollonian* and *Dionysian,* eventually a *Dionysian* culture became more predominant. More detailed Information on actions, practices and personal transformations which occurred as a result of this inquiry are discussed in chapters 7 and 8.

An ending of an inquiry is both a celebration and a sad time. A celebration for all which has been accomplished and sad because it is the end of what was inevitably a period of challenge, excitement and emotion where a bond was developed between inquiry participants. It is therefore important to allow time for participants to acknowledge and process that the inquiry has come to an end. With this in mind considerable time was allowed during the last session of this inquiry to reflect and for closure. The session was also followed by a shared meal.

The stages of co-operative inquiry are outlined in the spiral diagram in Figure 6

The Stages of Co-operative Inquiry
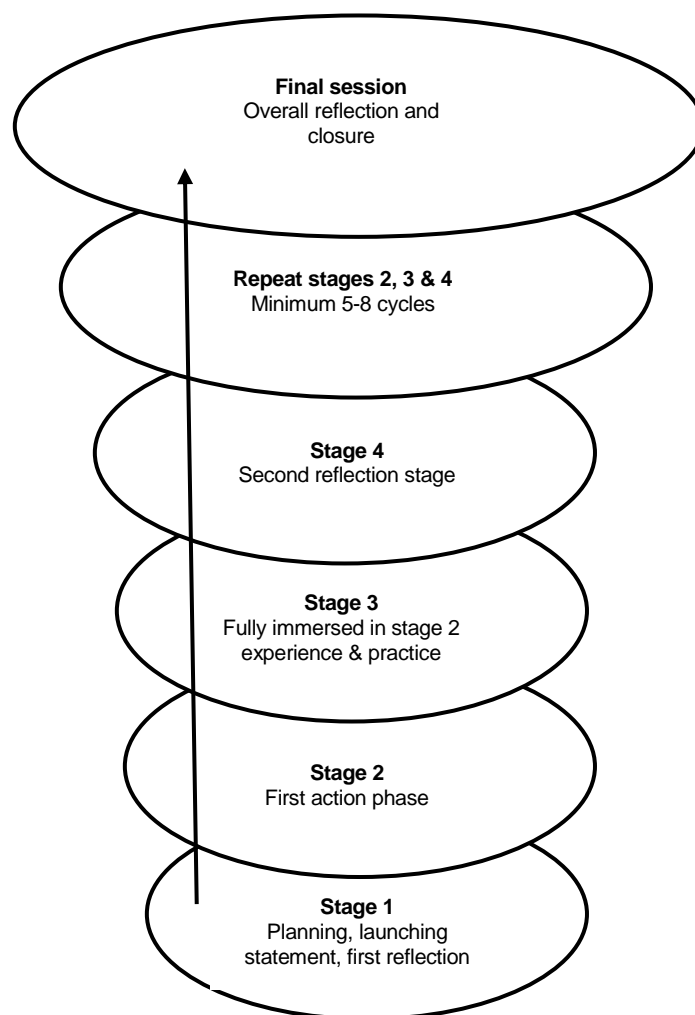
Figure 6: Spiral of cooperative inquiry

(Heron, 1996)

4.3.5 Analysis

As co-operative inquiry is an open process about discovery and learning and not about confirming or validating previous theories or hypothesis, to stay true to the methodology of co-operative inquiry there would usually be no (academic) analysis. However a critical analysis was a requirement for this thesis so a delicate balance was required to do justice to both the methodology and to fulfilling the academic requirements for this project.

In order to stay true to both the co-operative inquiry methodology and that of grounded theory[9] and for the reader to make the connections between the analytical findings and the origin of the data, and to ensure the researcher's ethical obligations were fulfilled, it was important the participants retained a degree of visibility in the text. To that end the analysis chapter has been called 'reflective analysis' and has been divided into three parts which are explained in more detail in chapter 8

Through the exploratory process of co-operative inquiry and its repeated cycles of action and reflection, patterns of behaviours, experiences and emotions emerged and key themes where identified which became the focus of the reflective analysis which are also discussed further in chapter 8.

4.4 Ethical considerations

Due to the nature and methodology used for this project, it was important the research be conducted in a moral and ethical manner. While ethical responsibility fundamentally lies with the researcher, approval also needed to be obtained from a regulatory body with an established and regulated set of standards to approve the research and to cover any legal ramifications (Anderson, 1988b). Because this research involved working with people, ethics approval was required from two sources.

As this these was being done through Unitec, an application for ethics approval was sought through the Unitec Research Ethics Committee and was granted in June 2008 (appendix A). Because participants were to be recruited through Positive Women Inc., it was also necessary to obtain permission from the Board of Positive Women Inc., to approach the organisations members before an ethics application could be made to Unitec.

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[9] Grounded theory is discussed in more detail in chapter 7

While the Unitec research ethics board is an established regulatory body with set standards, this was not the case for Positive Women Inc. It was therefore very important the Board of Positive Women Inc., were given sufficient time to examine the research proposal so as to fully understand the implications of the proposal and to enable them to seek advice if they needed. Permission to approach women from the Positive Women Inc. membership as well as my participation on the project was approved by the Board of Positive Women Inc. in March 2008.

Approval by Positive Women Inc. was given relatively quickly as the Board saw this project as a proactive undertaking which would hopefully empower women living with HIV who were affected by stigma and that the research might produce valuable information which Positive Women Inc., might utilise. A contributing factor was that the researcher was also a member of Positive Women Inc, providing extra confidence the research would be conducted in not only an ethical, safe and confidential manner, but also with an appreciative and understanding approach.

The main ethical principles considered in the preparation of this research project were:
- The avoidance of conflict of interest
- Minimisation of harm
- Maori and other cultural sensitivity
- Informed and voluntary consent
- Rights to confidentiality and preservation of anonymity
- Research design adequacy
- Intellectual and property ownership
- Limitation of deception

4.4.1 Avoidance of Conflict of Interest

A possible concern was that because of my role as the National Coordinator of Positive Women Inc., there may have been a perceived power imbalance if I were to facilitate the inquiry sessions. It may have been confusing and difficult for the participants to separate me from my leadership role in the organisation from that of the research project. It may also have been difficult for the participants to fully grasp and accept the project was to be a collaborative undertaking of which everyone was expected to participate as equals.

In an attempt to address this possibility, it was originally decided an independent person, Gabriela, would assume the role of facilitator. This person was a registered psychotherapist with previous experience in both group work and working with people living with HIV or AIDS. However after talking with John Heron (2008) who pointed out a

true co-operative inquiry did not call for an independent facilitator and the use of a psychotherapist could in-fact detract from the collaborative nature of the inquiry, it was decided it would be more appropriate for me to facilitate the co-operative inquiry sessions.

It was decided Gabriela would still be part of the inquiry process but attend the inquiry sessions in the capacity of a support person for the participants in the group. While this was still a deviation from a 'true cooperative inquiry', this was one of the areas I felt an adjustment could be made which would enhance the project and I believe it did. This is discussed further in chapter 4.4.2 under minimization of harm.

Because the women already knew me and knew I too was a woman living with HIV, I believe this helped to establish a sense of safety which allowed for greater trust and openness. It also meant I was able to fully be part of the inquiry as I was coming from a place of understanding and similar experience, rather than as an 'outside researcher'.

Deciding to facilitate and being part of the inquiry myself was one of the areas queried by the Unitec Research Ethics Committee and they required further convincing about this as they appeared to favour the use of an independent facilitator and that I participate as an observer (researcher), taking notes. It was explained my being part of the inquiry supported the concept of a co-operative inquiry in breaking down the separation between the roles of the researcher and the participants (Heron, 1996) and this was eventually accepted.

Although I did feel the need to take the lead from time to time during the sessions to ensure the group followed the action and reflection cycles of the inquiry, overall I do not believe there was any conflict of interest in regards to my role as facilitator or my participation in the inquiry. John Heron remarked during our discussion on 31 August, 2008 that it was actually acceptable for the facilitator to take the lead from time to time (Heron, 2008).

Participants were given a $20 petrol voucher each per session to cover the cost of petrol for them to get to and from the venue for the 5 weeks of the project but other than this no payment or inducements were provided.

4.4.2   Minimisation of Harm

Key considerations for this project were to ensure the physical and emotional safety and well being of the participants and that the research procedures did not needlessly put any of the participants at risk. Because all the participants involved in the project were

women living with HIV, it was important to recognise the project might arouse some emotions. To assist in this process, participants were informed of names and contact details of three psychotherapists working for the New Zealand AIDS Foundation whom they could contact for extra one-on-one support if they felt the need.

Gabriela was also present at all but one of the inquiry sessions. While Gabriela was a trained psychotherapist the role she played during the inquiry sessions was primarily in the capacity as a support person. This meant a rapport had already been established between the participants and Gabriela should anyone feel the need to contact her for extra support. Gabriela was also able to assist by watching for both verbal and nonverbal signs of unease, distress and the emotional safety of participants within the group as the sessions progressed and was able to address any issues immediately by asking questions to the group to check how everyone was feeling. However, overall there were no major issues and as it turned out no one (apart from myself) needed any extra support outside of the group during the inquiry process.

While the inquiry topic itself did not evoke any emotions for which I required support, I felt under considerable pressure because of the dual role I was playing in the inquiry. I needed to take time out of work to do the sessions and while I was trying not to 'lead' I was responsible for ensuring everything was organised and in place for the inquiry sessions. I was also anxious that the group follow the stages and cycles of a co-operative inquiry and was often anxious the participants might not attend the sessions. All of this was compounded by the limited time frame of the inquiry. These time restrictions plus balancing working full time and working on my theses meant I became stressed and anxious at times which Gabriela was able to support me through.

That none of the participant in the group felt the need for extra support I believe was due to the fact everyone felt very safe within the sessions. Even though Gabriela was a psychotherapist, her role within the inquiry was as a support person and not as a 'therapist' which I believe helped to reduce any feelings of being further stigmatised because of preconceived ideas of what psychotherapists do whereas being involved as a support person has a totally different connotation.

4.4.3   Maori Participation and Cultural Sensitivity

The aim of this research was to investigate how stigma affected women living with HIV in New Zealand. It was not within the scope of this project to research how stigma might affect different ethnic groups. Hence there was no separate selection on Maori or any other ethnic group. However, all women on the Positive Women Inc. data-base living in

the Auckland region were invited to join the project and there was a possibility Maori women as well as women from other ethnic backgrounds might participate.

In preparation for this possibility I consulted with the Unitec Maori Advisor, Nina Pelling of Nga Puhi descent and with my Associate Supervisor, Helene Connor who has iwi affiliations with Te Atiawa and Ngati Ruanui. However, as it turned out there were no Maori participants.

Three of the five women who took part in the research were New Zealand Pakeha, one woman was European and another woman was from Africa. Overall there did not appear to be any cultural barriers within the group. All the women had a good command of English so language was not a barrier. However as the facilitator it was important to be aware of cultural sensitivities. I believe the fact that two of the other women in the group had also lived in Africa and another had travelled extensively, meant most of the group was very sensitive and aware of cultural differences.

4.4.4 Informed and Voluntary Consent

When embarking on a research project involving human beings, the rights and welfare of participants is paramount and must to be protected at all times.

For this project, written informed consent was obtained from all the participants (appendix D). This was done firstly by way of a written explanation (appendix B) which was sent by mail to the women on the Positive Women Inc. database. This letter included an invitation for interested parties to come to a session were a verbal explanation would be given (appendix C). The nature and the purpose of the research, which covered the risks and the benefits, were explained fully during this session. It was explained participation was voluntary, confidential and that the process might also be of benefit to participants by creating a space for them to share their experiences and to dialogue. It was also pointed out that the project would be reviewed from time to time to ensure all these considerations were being met (Anderson, 1988a).

Following the verbal explanation participants were given the opportunity to ask questions and have any concerns answered. Once everyone was clear about the project they were invited to join the group. Everyone present at this meeting agreed and they were then asked to complete and sign a written consent form. It was explained even though they had signed this form, participants were still free to withdraw from the project at any time.

4.4.5   Confidentiality and preservation of anonymity

Due to my work as the National Coordinator for Positive Women Inc., I already had many years of training, experience and understanding around the need and importance of confidentiality and the preservation of anonymity as this is a core value of the organisation.

The participants were informed their names and anything which might identify them would not be used in the writing of this thesis. Individual names were not even used in the data collection process.

Participants were informed they would be able to read through all transcripts to ensure their confidentiality had not been compromised in any way and that anonymity had been maintained to their satisfaction.

Participants were also informed copies of the tape recordings and their consent forms would only be seen by myself and my supervisors and these documents would be stored in a safe and secure filing cabinet at my home.

4.4.6   Design Adequacy

Even though the process of co-operative inquiry is fluid and did not necessitate as much preparation as might be needed for another method of research, it still required structure and careful planning.

Prior to the start of the inquiry sessions, a number of meetings were held with Gabriela (support person) and Simon (data recorder) to ensure we all understood the process of the project. Gabriela read John Heron's book on co-operative inquiry to ensure she fully understood the methodology. This was very important as she was initially to facilitate the sessions. As it turned out she did not facilitate the inquiry sessions but it was still important for her to have a good grasp of the process in her role as support person.

An outline was put together about what needed to be covered during the first session (appendix C) which was discussed in advance by the three of us to ensure every aspect of the project was covered and to ensure all three of us fully understood our roles. There was also a short debrief after or just prior to each session between the three of us to ensure we were all well prepared and to review the session to ensure everyone was safe and that the project was moving through the cycles and phases of a co-operative inquiry.

No external funding was obtained for this project. The main costs involved were the petrol vouchers and a small fee for the person who did the data recording. A private and safe venue was secured to hold the inquiry sessions over the 5 week period at no charge and Positive Women Inc. agreed to cover some general expenses such as paper, and time off work for myself, towards the research.

4.4.7   Intellectual and Property Ownership

Being a co-operative inquiry, ownership of the research outcomes needed to be clearly identified at the start of the project. This was done during the first session. It was explained to the participants that as I was the researcher and would be writing up the final analysis, ownership of the research for the purpose of the theses would belong to me, but outcomes and actions as a result of the enquiry would belong to the group. It was also acknowledged any incomplete actions might be passed on to Positive Women Inc. for further action and would then become the property of Positive Women Inc.

4.4.8   Limitation of deception

Participants were fully informed both verbally and in writing of the intentions of the project. They were also informed they would be able to read through all transcripts to ensure there was no deception of purpose and that confidentiality and anonymity had been maintained to their satisfaction.

4.5   Data Collection

When undertaking a qualitative research method such as cooperative inquiry, the collection and recording of data is fundamental. A variety of methods for recording data were used for this project, these were:

4.5.1   Demographic Information Forms

A brief quantitative questionnaire was presented to the women during the first session to capture some very basic demographic information about the participants (appendix E).

The reason for collecting demographic information was to compare if things such as age, length of time diagnosed or whether or not the women were on medication, had any impact or correlation to other data collected. This has been mentioned briefly here as it was one of the forms of data collection but it is discussed in more detail in chapter 8.3.I.

4.5.2   Mind Maps

The main form of data collection for this project was done by recording key themes of the discussions on mind maps (appendix F). This was done by an independent recorder/scribe.

The person (a woman) who was initially approached to do the mind maps was not available when we needed her and after discussions with a friend, she suggested approaching her partner, Simon, as mind-mapping was a technique he was familiar with.

The mind maps, which captured the key concepts and themes discussed by the group, were drawn on large AO (841mmx118mm) sized sheets of newsprint which were tacked to the wall at the back of the room during the inquiry sessions.

Using mind-maps as a way of recording was a visual and immediate way for participants to see what had been discussed throughout the session. It was also an effective way of data reduction in that only key themes or statements were recorded focusing on the real issues making it easier for data recall when it came to writing up the events of the sessions. From a personal perspective I preferred the use of mind maps over linear note taking as it was more visually stimulating and multi dimensional enabling clearer associations between key words and themes as opposed to searching through screeds of written notes (Buzan & Buzan, 1993).

The advantages of mind mapping over recording and transcribing or for linear note taking, were that it saved time by noting only relevant words, associations were made between key words and it was also easier to mentally process multi dimensional and visually stimulating mind maps over tedious notes (Buzan & Buzan, 1993)

As well as being a key data recording method the mind maps also played a number of crucial roles throughout the inquiry session. Towards the end of each inquiry session the group spent time going over what had been recorded to ensure data had been recorded accurately and this process also helped to put all contributions into context. Participants were encouraged to add anything they felt may have been left out, or to add anything new which they had not previously considered thus increasing energy and cooperation within the group and encouraging ownership of the process (Buzan & Buzan, 1993). This time was also used to reflect on what had been discussed and as a process to assist with helping the women to decide on the next action phase of the inquiry.

After each inquiry session the mind maps were reduced to A4 size and copies were sent to participants before the next session. The purpose of this was to provide the women with a record of what had been discussed during the session enabling them to reflect on these in their own time and could also be used as a source of reference to remind the women of the actions which had been decided and thus increase the probability of stated actions being accomplished (Buzan & Buzan, 1993).

Consideration was given that the presence of an independent recorder might be disturbing for the participants, especially as he was technically an outsider to the inquiry and this was not being true to the methodology of cooperative inquiry (Heron, 1996). Consideration was also given to the fact the women might not feel comfortable about having a man present as this might inhibit discussion, however this concern proved to be unfounded as a close rapport was very quickly established between the participants and Simon (and Gabriela) who were both required to sign confidentially forms. The women appeared comfortable, speaking openly and honestly and shared their experiences, thoughts and feeling without reservation, which highlighted flexibility was acceptable to make changes or adaption to the methodology especially one as fluid as co-operative inquiry (Cook, Crouch, & Katzer, 1991: Davidson & Tolich, 1999).

From a researcher's and co-participant's perspective I found it especially beneficial having a third party doing the mind mapping/data recording as it allowed me the freedom to be totally immersed in the sessions as a co-subject.

A disadvantage of having a third person do the recording was that the key words and concepts captured were those of which the recorder found to be most significant. While recording should in theory only be about noting what was said, there was still undoubtedly an element of interpretation. Had I taken the notes myself I may have chosen to focus on different aspects of what was being said. However on the positive side, (and there were many more positives than negatives), as the recorder was both a man and not a person living with HIV he was hearing/listening from an unemotional and uninvolved perspective whereas had I done the recording myself I may have been listening and recording from a preconceived or even a personal perspective (Cook et al., 1991). One of the characteristics of co-operative inquiry is that all participants are co participants or co-subjects which enables a depth of understanding not generally able to be captured by an 'outsider' (Heron, 1996). However, it is worth nothing Simon did not feel like an outsider nor was he perceived as one.

One of the participants commented she actually felt more comfortable knowing Gabriela and Simon where a couple as it added to her feelings of safety and sense of security. She felt because they were a couple they would be less likely to discuss anything about the inquiry session with anyone outside the group. What she indicated when she said this was that as the recorder and the support person were a couple, they would probably only talk with each other and as she knew both of them, she somehow felt a sense of control over knowing who knew about what was being said in the sessions and who knew she was a woman living with HIV. If the recorder and the support person had not been partners it was perceived there may have been more potential they might share what was happening within the group with others outside the group and subsequently there would have been an element of 'the unknown' and a sense of 'a lack of control' on the part of the women. As both the recorder and the support person had signed confidentiality forms, in theory they probably would not have told anyone else regardless of their relationship with each other, but this again is an indication of the depth of fear people experience when living with a stigmatised disease such as HIV.

4.5.3   Tape recording

Each session was audio-tapped as well as having data recorded on the mind maps. Participants did not seem to be distracted or feel uncomfortable with the use of the tape recorder and again from a researcher and co-participants perspective, I found it beneficial to have the sessions audio-taped (as well as doing the mind maps) as it allowed me to be fully immersed as a co-subject during the inquiry sessions. Also while the mind maps captured key concepts and themes, they did not capture everything and it was beneficial to be able to listen to the tapes to elaborate on discussions to fill in gaps and to draw out quotations.

The audio-tapes were not transcribed as the mind-maps were used as the primary means of data recording and it was felt these would be more than adequate. However on reflection it would have been beneficial to have had the recordings transcribed as it would have been efficient use of time to have been able to read transcripts rather than listening to (5) two hour long tape recordings.

4.5.4   Journals

Participants where provided with a personal journal so they could write down their own reflections, leanings, actions and outcomes. While these could also have been used as another source of data collection to assist in the analysis process (Bray et al., 2000), I felt the mind-maps and audiotapes would capture sufficient data for recording purposes. I also thought the women might be more inclined to write what they really felt if they knew

the journals would not be seen by anyone else. As it turned out some women chose not to use them at all. The women who did use them only did so to record outcomes from the actions they undertook in-between the inquiry sessions or to jot down a question or query to bring to the next session. None of the women used them as a journal to chronicle their thoughts or emotions on the topic of HIV and stigma. This was mostly due to the fact they were all very busy in-between the inquiry sessions and commented the sessions came around so quickly they had not had sufficient time to do much else apart from the actions they had committed to.

4.6 Participants

Participants for the project were recruited from the membership of Positive Women Inc. As the research methodology recommends a minimum of five meetings to be truly effective (Heron, 1996), and due to limited funding, only members living in the Auckland region were approached as geographically it was easier for the group to meet on a regular basis.

A personal mail-out was sent to each woman (appendix B). This letter explained the purpose of the project and invited women to attend a meeting to find out more information about the project and also provided an opportunity for them to ask and have answered any questions they may have had. This was to ensure everyone was fully informed about the process and to provide the women with an opportunity to either consent or decline to be involved.

It took much longer than anticipated to recruit participants for the project which was unexpected. Some of the women commented they were working and did not have the time or energy to participate, while others did not like the idea of working in a group. As a result the first meeting did not take place until 3 September, 2008 which put the project considerably behind schedule.

The original intention was to have about eight participants but in the end four women, and myself (a total of 5) agreed to take part in the project, which according to Heron, is a sufficient number for a co-operative inquiry (Heron, 1996). The advantage to having a smaller group size was that participants had more opportunities to speak enabling more in-depth discussions and ensured everyone was able to have a say. The down side to only having five participants was that due to unexpected events which occurred in their lives during the time frame of the project, not all the women could make it to all the

sessions so the inquiry sessions ran with participants ranging from five to three over the five week period.

While this was a relatively small sample, it did however provide an opportunity for a more detailed study on the social lives of a small group. This being said, according to Davidson and Tolich (1999), it is thought when all things are equal, a sample of 5 from a population of 100 will as accurately represent a population of 1000 as it will a population of 10000, just as it only takes a sip from a bottle of wine to know what the rest of the wine in the bottle will taste like (Davidson & Tolich, 1999).

Once the women had been fully informed, both in writing and verbally and had their questions answered they were asked to sign a form giving their 'informed consent' to join the project. Each woman was also asked to sign a confidentiality form. Blank copies of these forms have been included in the appendices (appendix D).

4.6.1   Demographic Information

To ensure the confidentiality of the women who took part in this project it was decided no names would be used as it was recognised even when using aliases (made up names), a reader could still possibly identify a pattern by what a particular person was saying which could inadvertently disclose their identity. Not feeling comfortable referring to the women as a number, plus patterns and identities could still be determined through the use of numbers, it was decided the women would be referred to in the third person. i.e. one woman said, another woman said and so on. While this was a conscious choice it is recognised this could be confusing from time to time however it was felt this method better safeguarded the identity and confidentiality of the participants, which was the main priority. The only exceptions to this has been in figures 7 and 8 and in the 7 month follow-up were there seemed no alternative but to identify participants as numbers.

When using quotes made by the women these have been referenced as 'Participant, personal communication' followed by the date the quote was made.

The women who took part in the project ranged in ages from 32 to 51 years so there was a good balance in that regard although ideally it would have been valuable to have had at least one woman in the 18-26 age group so we could have had a youth perspective.

Three of the women had been living with HIV for 15 years, one for 20 years and one for 4 years. Interestingly it was the three New Zealand Pakeha women who had all been living with HIV for 15 years but I do not think there was any relevance in this fact, just coincidence.

Three women had CD4[10] counts between 500-1000, two women had CD4 counts between 200-300. All had undetectable viral loads and were in good health.

Three of the women had children. Of these, two of the women's children knew about their mother's HIV status, one did not. This information can be more easily seen in the graph in Figure 7.

Disclosure Information

Participant	1	2	3	4	5
Age	32	37	47	48	51
Ethnicity	NZ Pakeha	African	NZ Pakeha	NZ Pakeha	European
Number of years lived in New Zealand	32	4	32 15yr *OE	43 5yr OE	30 17yr OE
Number of years been living with HIV	15	4	13	15 ½	20
Number of years on ARV medications	3	4mths	6mths. Twice before with 3yr break each time	5yrs & 9mths with 5yr break	16yrs
Last CD4 Count	500+	270	249	715	980
Last viral load count	undetectable	unknown	didn't answer	undetectable	undetectable
Married/steady relationship	yes	Recently separated	no	yes	no
Number of years married or in relationship	1mth	n/a	n/a	15yrs	n/a
Number of children	n/a	1	3	n/a	1
Ages of children	n/a	16	18,16,14	n/a	24
Children aware of HIV status	n/a	no	yes	n/a	yes

Figure 7: Participant Demographic Information
* OE = Overseas Experience

When collating the data from the demographic information questionnaire it became evident some of the questions had not been very clear. Most questions only required a tick bit some of the tick box questions had not been answered. On reflection the

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[10] An explanation of the significance of CD4 and viral loads has been provided on page 7.

questions required clearer instructions or could have requested a yes/no response rather than a tick box, highlighting the importance of adequate questionnaire design (Floyd & Fowler, 1995). Consequently the forms were re-presented to participants, with cleared instructions on what to do.

While Davidson and Tolich believe qualitative research is predominantly about doing a detailed study on the social lives of small groups and with all things equal, smaller sample sizes can be representative of a larger population (Davidson & Tolich, 1999), it needs to be acknowledged there may have inevitably and unintentionally, been some bias in the recruitment of participants for the project. Firstly only women who were members of Positive Women Inc. living in the Auckland region were invited to participate and it took three approaches before volunteers came forward. While these women were representative in that they were women living with HIV, according to Cook et al. people who volunteer in studies can add a bias because it is thought volunteers are generally better educated, less authoritarian and are generally better adjusted than non volunteers (Cook et al., 1991).

Some of the reasons it took so long to get women to sign up for the project may have been to do with women not wanting to explore the subject of HIV and stigma which is a sensitive topic for those affected. In many cases there is even an element of denial, which is more to do with a sense of self preservation and protection than anything to do with pretending HIV does not affect them. This was evident when I spoke with some women after completing the project who told me they had not participated in the inquiry as they did not feel affected by stigma. I was surprised to hear this as I knew very well the stories of these women and some were most definitely and quite strongly affected by stigma which lead me to believe they either did not fully understand what stigma meant or they were in either a conscious or unconscious level of denial.

Some of the African women commented they did not want to be in a group where there might be other African women as they feared these women might disclose their HIV status within the African community which was something noted by Burns et al., in their study in Britain (Burns, Fenton, Imrie, Johnson, & Nazroo, 2007). Ironically, from my experience as the National Coordinator of Positive Women Inc., I have never once seen or heard of this happening as these women are all living with HIV and do not tell, or talk about each other as they are all affected (J, Bruning, Personal Communication November 7, 2008). Where this is more likely to happen is when one woman is not HIV positive and knows about someone who is (Gibson & Rohleder, 2006).

4.7   Summary

This chapter has discussed the four cornerstones of knowing and how this applies to co-operative inquiry as a research method as well as the links between co-operative inquiry, qualitative and action based research methods.

The theoretical cycles of co-operative inquiry were broken down into the four main stages and the importance of each stage/cycle was discussed. These discussions highlight the importance of taking time and care to ensure the structure of the inquiry is clear, but also that through reflection and evaluation, these processes can be adapted to better fit the needs of the inquiry.

I was initially surprised and somewhat disappointed it took nearly three months to get enough women to join the research project and that I was only able to recruit five women in total, which included myself, however the women who did come forward were amazing as they all immersed themselves into the inquiry, and fully participated.

The mind maps were a great visual reference when writing up the data. It gave an overview, on one or two pages of all the key areas covered in a session.

From a personal perspective, co-operative inquiry was a good fit in that it was an inclusive method of research and one which aligned closely with my own personal values and beliefs. Davidson and Tolich point out it is quite common practice for a researcher to look for a research method which fits closely with their own personal values, beliefs and even personalities (Davidson & Tolich, 1999).

What became very clear is that research does not always fit simply and clearly within just one discipline and at times requires a variation of methods. Davidson and Tolich state there is no such thing as one best research method and that research should always be tailor-made (Davidson & Tolich, 1999).

5 Theory

5.1 Introduction

A chapter on theory may seem to contradict the underlying methodological principles of co-operative inquiry as co-operative inquiry is inductive and not about confirming or validating preceding theories or hypothesis (Heron, 1996; Bray et al., 2000). Because this research project was undertaken as part of a master's degree, there were however various academic requirements which had to be met and as a result some deviations were made in order to comply with those requirements. The 'purest' follower of co-operative inquiry may find these deviations appear to flaunt the fundamental principles of co-operative inquiry. Never-the-less even Heron (1996) concedes there is more than one way to carry out a co-operative inquiry.

A number of theories were considered in the formulation of this project. As the project was about women, feminist theory was reviewed especially with its connection to constructionist theory. I was also drawn to grounded theory as I felt it had a convincing correlation with co-operative inquiry and also with feminist and constructionist theories.

Bonner, Francis and Mills (2006) wrote a compelling paper on "*Adopting a constructivist approach to grounded theory: Implications for research design*", which appeared particularly suited to this project as did a conference paper by Brine (1994) on "*The use of grounded theory within "Feminist" research*". As a result I decided on 'Feminist Grounded Theory' as the best fit for this research.

This chapter will explain the process of feminist grounded theory and its application in regards to this project.

5.2 Feminist Grounded Theory

5.2.1 Feminist Theory

There are many different and sometimes conflicting approaches to feminist philosophy. In an attempt to provide a representative approach to feminism Susan James (2000) describes feminism as:

> ………grounded on the belief that women are oppressed or disadvantaged by comparison with men, and that their oppression is in some way legitimate or justified. Under the umbrella of this general characterization there are, however, many interpretations of women and their oppression, so that it is a mistake to think of feminism as a single philosophical doctrine, or as implying an agreed political program (cited in Tuana, 2004, p. 5)

As a woman who previously has not identified as a feminist, which some feminists might imply could be due to the lack of recognition of my own oppression, I initially struggled with the concept of feminism and feminist theory in any of its many forms, until I came upon the following comment by Tuana (2004).

> …..the fact that one is or appears to be a woman need not be the only factor relevant in explaining the injustice (or oppression). It might be, for example, that one stands out in a group because of one's race, or one's class, or one's sexuality (*or disease*), and because one stands out one becomes a target (Tuana, 2004, p. 10).

Franklin and Stacey (1988) argue there is a strong correlation between various feminist theoretical perspectives which attempt to describe, explain and analyse the conditions of women's lives and social constructionism (Bartkowski & Kolmar, 2005 pg 2), which is also about change, discontinuity and contradiction and are perspectives commonly intertwined in feminist theory (cited in Richardson & Robinson, 1993).

For example, feminist theory might suggest stigmatisation occurs in the lives of women living with HIV and their relationship with stigma, is due to men's power over women both economically and socially, but more significantly in regards to control in sexual relationships as usually women have less control in sexual encounters than men. This is significant considering HIV is generally a sexually transmitted disease. It is not commonly accepted that women are 'sexually liberated' and the double standards which apply in this regard, where men may be considered 'macho', 'Romeos' or 'care free bachelors', while social constructions, labels and metaphors for women are not generally so complementary with women often being referred to as 'promiscuous', tarts', 'slag's', 'sluts', 'whores' and the list goes on. However as has already been mentioned, even amongst feminist theorists, views differ as some feminist are more concerned about the rights of women to refuse unwanted sex as opposed to seeking sexual liberation (Richardson & Robinson, 1993).

Richardson and Robinson (1993) pose the question, "What is sexuality?" then explain sex is something which happens naturally, it's instinctual, it is something which is part of our biological makeup. It is a reproductive activity and happens between heterosexual couples through vaginal intercourse. This being an *essentialist* view of sexuality which is based on biology and human nature and suggests change is difficult to achieve. Whereas feminism based on social constructionism is to believe that our sexual feelings and activities and the way we think about sexuality are not merely biological but are products of social and historical forces shaped by culture, religion and laws and while our

sexual desires may seem 'natural' our sexual responses are actually learnt which also includes meanings that are attached to behaviours which can also lead to stigmatisation.

Because HIV was initially associated with gay men it was primarily constructed as a 'gay man's disease'. Much research and education, particularly in New Zealand, is focused on gay men while women remain invisible and isolated which highlights the 'powerlessness' experienced by women in New Zealand living with HIV, reflecting the overall position of women in society (Bennett, 2007).

It is however important to recognise gay men living with HIV are also doubly stigmatized, firstly because they are gay and secondly because they have HIV.

What was emerging, for me, was that a fundamental characteristic of feminist theory and research requires a focus on women and so it began to feel like a suitable fit.

5.2.2   Grounded Theory

I was initially drawn to grounded theory because its fundamental starting point is in the actual experiences and understandings of the people being researched (Brine, 1994).

Grounded theory originally evolved from the work of Glaser and Strauss (1967) who first introduced the concept in their publication *The Discovery of Grounded Theory* in 1967. An interpretative research methodology. The main principle of *traditional* grounded theory is to produce new concepts and theories and is often used by social researchers to uncover social processes of relationships. It is useful in understanding the behavioural patterns which emerge within groups as people identify situations which are common in themselves and others in the group. One of the main strengths of grounded theory is it explains what is actually happening rather than suggesting what 'should' be going on (McCallin, 2003). This is done through a process of data collection which is *inductive,* where the researcher is expected not to have any preconceived ideas to prove or disprove and as such, together with a feminists underpinning, was distinctly compatible with the methodology of co-operative inquiry.

It is a challenging research theory which is not without its problems specially when working in isolation. Its 'looseness' lacks many of the rules and procedures for conducting research and it requires considerable 'open mindedness' on the part of the researcher while still necessitating knowledge of the topic.

As a novice researcher I was initially daunted at the thought of using grounded theory as I was nervous of being required to *generate* theory. Another concern was the size and

the limited time frame of this project which I feared would not be large or long enough to enable the generation of theory, but McCallin (2003), and Denscombe (1998) stated, theoretical development does not need to be the main goal of a small project. What was more important was that the researcher was capable of analysing the data. This was reiterated by Glaser (1998) who stated that in smaller projects it would be enough to describe and explain underlying social processes shaping interaction and behaviour (cited in McCallin, 2003). Once I had accepted it was probably unlikely any theory would be generated but that this would not be detrimental to the project, I felt more confident.

Another consideration was a statement made by Glaser (1992) who argued the use of *traditional* grounded theory required the researcher not review any literature on the area under study as this would constrain or inhibit the researcher's analysis of the data (Bonner, Francis, & Mills, 2006). This was problematic as a literature review was most definitely a requirement in the writing of this thesis.

It was Strauss and Corbin (1994) who moved from the *traditional* to an *evolved* grounded theory, suggesting theories are embedded in history and by engaging in the literature from the beginning of the research process; this would assist the process by contributing another voice to the researcher's theoretical construction of the data. Corbin went as far as to say that '*theorising is the act of constructing'* (cited in Bonner et al., 2006, p. 4). This approach then seemed to allow for the provision of a literature review.

Charmaz (2000), a student of Strauss and Corbin, took their theory one step further by arguing a constructivist approach to grounded theory was both feasible and favorable. Charmaz argued, data alone did not provide a position on reality, but instead the 'discovered' reality evolves from the process of interaction and its wider, cultural, and structural context which requires searching for and questioning of, unspoken meanings about values, beliefs and ideologies. In this regard, Charmaz believes the researcher can be positioned as the co-producer, encouraging participants and then 'adding' a description of the situation or the interaction and their perception of how the inquiry went.

How the data is managed and the analytical outcomes of the data are significant and Charmaz advocates the raw data needs to be maintained as much as possible to ensure the participants voices and meanings are present in the theoretical outcome which was in line with the methodology of co-operative inquiry, yet this constructivist approach also allowed for the researcher to position themselves as the author of the reconstruction of the experiences and meanings.

Grounded theory, with a constructionist leaning, is an interpretive methodology which stresses that as human beings we decide what to do in the light of our interpretation of the world around us, or in other words, we choose what to do according to our personal definition of a situation (Jones, 1991). This means there is often no right or wrong, just our own personal interpretation of how things are. Gadamer believes understanding and interpretation are intrinsically interwoven and an evolving process so a definite interpretation may never be possible (as cited in Laverty, 2003). This can influence how we respond to a situation because as humans, we will often act in ways we consider appropriate to a certain situation, and what we consider appropriate will depend upon what we *think* the behaviour of others means (Jones, 1991). So no matter which approach of grounded theory was used, it was likely that the analyses would be influenced to some degree by the researcher.

Symbolic interactionism is the name given to one of the best-known of interpretive theories (Jones, 1991). Human beings often aspire to be independent and unique, yet on another level there is a strong need by people to be accepted by society which is perceived to be attained by maintaining a degree of normalcy (Dolan, Mallinson, & Relf, 2005). A person's self esteem comes largely from being connected to others in a meaningful way and when this is absent, people can feel worthless and unloved (Evans, 1994). However defining 'normalcy' in the area of social science is not as clear cut as in the medical sciences as it is more about philosophical, metaphysical or even superstitious assumptions (Kuehlwein & Rosen, 1996).

According to Fisch, Watzlawick and Weakland (1974) the basic structure of social constructionist theory is when a significant number of people in a community apply a definition (language or label) to something, which is then viewed as a viable reality, The process of how this reality came about is forgotten as the 'constructed' reality comes to the foreground and is accepted as the reality, which is exactly how stigmatization is manifested.

Gergen (1991) believes society's perceptions of reality are generated by the use of language and preferred vocabularies (metaphors/sterotypes) constructed by certain sectors of the community. These vocabularies are then used to reflect a community's way of living and become a reality because they appear to be very convincing and imply those who do not agree or do not understand are lesser beings than those who accept and agree. An example of this would be when the earth was thought to be flat, which was a '*perceived*' reality. However concepts of reality can and do evolve as was the case when it was eventually discovered the earth was in fact round. Ironically even with

supposed empirical proof, it took a long time for many people to accept this as a reality, and some never ever did. This example provides an indication of how stigmatisation can also evolve within societies.

Bruner (1986) suggests there are two types of thought processes by which reality is constructed. One is the *paradigmatic* mode which is defined in terms of science and logic which looks for truth through empirical proof. The other is that of *narratives* which is based on the construction of stories and their context. Everyone has a story to tell and often the act of telling or sharing these stories with others can bring new meanings and perspectives to people's lives. For some the telling of their story can have a healing effect or at least, a soothing benefit and can even result in a change in beliefs or social views.

This study attempts to express 'the truths about (some) women's lives' in relation to living with HIV and stigma through the sharing of *their* stories, as some feminists might argue, on a gender which has already been stigmatised for centuries through social constructionism for the mere fact they are women.

5.3   Summary

Feminist grounded theory facilitates a process which allows the research to move from 'the ground'. This is particularly constructive in feminist and other areas of social justice research because it allows for the generation of theory to be grounded in the actual experience and understanding of the women being researched. This is not necessarily done in a predetermined way but through capturing concepts which emerge from the methodical analysis of data. However, as indicated by Charmaz (2000), the researcher can still be a co-producer, by motivating participants and then 'adding' their interpretation.

The use of co-operative inquiry as a methodology for this project, which provided women the space to tell and share their stories through narratives and to engage in actions, was an obvious fit with feminist grounded theory in that the research focused on the human experience and by addressing gender issues, eliminating power inequalities and acknowledging women as the experts in their own lives (Bennett, 2007).

6   The inquiry process

6.1   Introduction

With methodology, data collection, participation, theoretical and ethical considerations and approval obtained it was time to commence with the actual research project.

This chapter will discuss the practical application of co-operative inquiry as it applied to this project. Discussions will include an explanation of the inquiry process on a session by session basis with a focus on the actions undertaken by the women over the period of the project.

6.2   Co-operative Inquiry Sessions

For this project the inquiry was done through a series of group meetings. It was agreed by the participants the group would meet on Wednesdays for 2 hours from 10 am till 12 pm for a period of 5 weeks as this was the most convenient time for the majority of the women. The first session took place on the 3rd of September 2008 and the final session was held on the 1st of October 2008.

One woman indicated she might not be able to attend all of the sessions due to work commitments but said she would try to be present at as many meetings as possible.

6.2.1   Session One

The first hour of the first session was spent explaining the framework of the project and the process of co-operative inquiry to the potential participants (refer to appendix 2). At this stage the women were only potential participants as they had not yet been provided with enough information to enter into an informed consent agreement.

This session was facilitated by me in my capacity as the researcher and was the only time during the five weeks that I visibly and intentionally lead the group.

Once the proposed framework and processes had been explained and everyone's questions were answered the women were officially invited to participate in the project. All the women accepted the invitation and then completed written consent/confidentiality forms. Each participant was also asked to complete a short questionnaire to provide some demographic information for the project (appendix E). The group decided they would complete the demographic questionnaire at home and bring them back at the next session. A short tea break followed.

During the second hour of the session, some questions were asked to initiate discussion. While these were relatively loose, open-ended questions they were however specific in that they encouraged discussion around the women's own personal understanding and experiences of stigma and how, or if, it affected their lives. These questions were initiated by me but once discussion started I then pulled back from the facilitation role and the group then entered into the true co-operative inquiry phase with all participants at this stage being co-subjects.

It was important the discussion process stayed as close to each person's lived experience and it was just as important to be aware of what was 'not' being said as to what 'was' being said. Reading between the lines and paying attention to silences were all critical aspects. It was also important to be aware about making assumptions on what any silences may have meant (Laverty, 2003).

For the last 15 minutes of the session the women gathered around the mind-maps and Simon verbally summarised what had been recorded. This was to ensure everything had been accurately recorded and also provided an opportunity for the women to add anything else if they wanted and to foster a sense of ownership. Going over the mind maps together like this also provided the women with an opportunity to have both a visual and verbal overview of the session and to reflect on what had been discussed.

Being the first session a considerable amount of time was spent on setting up the framework for the project and as a result there was not enough time for any 'actions' to evolve so it was decided the action over the next week, besides completing the demographic questionnaire, would be for each of the women to think about what actions both as a group, or as individuals, they might realistically be able to, and want to, work on.

6.2.2   Session Two

The second session opened with a check-in by each of the women in the group. The check-in was an opportunity for the women to share what had been going on for them since the last session and to allow time for everyone to come together, to connect.

The women spent a considerable amount of time during the first part of this session sharing their thoughts and feelings about things which had come up for them as a result of discussions during the first session, or about things which had occurred during the week around HIV and stigma which they had become more aware of because of the

discussions from the first session. It was evident even after only one week that the inquiry had raised the women's consciousness and awareness to HIV and stigma.

It was through this sharing of experiences, feelings and emotions that a common concern started to appear in the discussions. This was around the apparent lack of understanding teachers in secondary schools seemed to have of how HIV was transmitted and how the misinformation being provided by the teachers to the students helped to feed into the stigma associated with HIV. It was from this discussion that the beginning of the first action of the inquiry began to emerge.

One of the women shared a story of her daughter's experience during a sex education lesson at school.

> The teacher informed the students HIV was transmitted through bodily fluids and then asked the students to identify some bodily fluids through which HIV might be transmitted. One of the students in the class suggested sneezing, to which the teacher said yes, as sneezing involved saliva which is a bodily fluid (Participant, 10 September, 2008).

The daughter of this woman, who was aware of her mother's HIV status, while shocked at the teacher's response, was hesitant to say anything in case the class might enquire (suspect) how she knew this was not correct. An indication of the profound depth of the stigma of HIV in that this young girl was too afraid to share her knowledge of HIV in case she be marked or labeled in some way.

During the same lesson the teacher informed the class that people with AIDS (it was not referred to as HIV), had about a 10-12 year life expectancy. When the woman's daughter came home from school that day she said to her mother, "You should be dead by now mum" (Participant, 10 September, 2008).

While this information was not totally incorrect, as life expectancy without medication is expected to be between 10-12 years (Thomas, 1999), it wasn't explained that with the advancements in medications life expectancy for people living with HIV is now much longer.

This story alarmed the women in the inquiry group and instigated a discussion on the lack of education around HIV. The women felt education about HIV should start at schools as it was important for young people to know about HIV at an early age, not only as a means for prevention but also as a means of raising awareness so as to reduce stigma.

It was also recognised that teachers needed to be educated about HIV and AIDS to ensure both they and the students had access to correct information.

An action was proposed to investigate how/what sexual education was conducted at secondary school level, specifically in regards to HIV and what resources where available for students and teachers.

The group questioned how this action linked to HIV and stigma and after some discussion concluded that misinformation around HIV contributed towards the misunderstandings and misconceptions around HIV which helped to foster stigma and the subsequent discrimination of people living with HIV.

Someone questioned how much impact the actions of a group such as this could really have. Another woman shared a poem she had recently read.

> It was about two men who came across hundreds of starfish which had been stranded on the beach as the tide had gone out. One of the men picked up a starfish and threw it into the sea and then proceeded to get another starfish to do the same. The other man commented "there are so many starfish on the beach, you can't possibly make a difference?" to which the other man replied, as he threw another starfish into the sea, "well, it made a difference for that one" (Participant, 10 September, 2008).

This poem became a metaphor for the group. The women decided even if what they did only made a difference for *one* person, then at least they would have made a difference for someone. They also decided that even if what they did made no difference at all, at least they would have tried and there was an acknowledgement by the women that through experience and participation the outcomes of the inquiry would be *transformative* for themselves even if not for anyone else. Both Heron (1996) and Aggleton et al., (1998) reiterate the process of co-operative inquiry can be transformative and is in itself a form of intervention, empowering those affected by stigma (Heron, 1996; Aggleton et al., 1998).

The women decided on an area they wanted to work and each woman then chose various areas to investigate around HIV education at schools.

- One woman chose to approach the headmistress at the school which her daughter attended to ask what the school curriculum included around HIV education and awareness and what resources the school used. She would also search for HIV resources from sexual health clinics and the Citizens Advice Bureau to see what sort of resources where available.

- Another woman chose to contact Family Planning and to investigate the Ministry of Health guidelines.

- Another opted to contact a friend who was currently training to be a teacher and on placement at a school to see what was being done at that school in regards to HIV education and also to see if there was any training being done on the topic at the teachers training college.

- Another woman chose to speak with the Sexual Health Clinic at Auckland Hospital as she knew they ran specific sexual health educational weekends for secondary schools.

- Another woman said she would talk with her son to see what was being taught at his school.

It was realised at this stage of the session that the original format proposed in session one, where actions would be decided after reflection of the mind-maps, was not working. On further reflection of the process it was decided the original format would be changed and actions would now be decided before the summary of the mind-maps as this felt more natural. This also meant the actions would be included in the summary and on the mind-maps and would be included on the scaled down copies of the mind maps sent to the women to keep as a personal record of what had been discussed during the session and a reminder around actions agreed upon.

6.2.3   Sessions Three

Session three, as per session two, started with a check-in round. This was a space for the women to talk about what had been going on for them emotionally or otherwise during the week and provided a space for everyone to come together and to reconnect.

After the check-in each of the women reported back on the actions they had undertaken over the week.

"I chickened out of going to the school" (Participant, 17 September, 2008) reported the woman who said she would approach the headmistress of her daughter's school. She said the principal of the school was away and would not be back for the rest of the term. She explained how she could have spoken with the assistant principal but when it came to the crunch she said,

> It was too scary. I don't know the assistant principal very well and I don't know if I can trust the people at the school to treat me and my children right (Participant, 17 September, 2008)

She discovered however the school showed a DVD to the children and said she would try to get a copy of the DVD. This woman also visited other institutes and collected a number of resources on HIV awareness and prevention which everyone looked through and which generated more discussion.

Another woman said she had not heard back from her friend at teachers training college but instead had phoned a teachers training college. She reported she had initially been given the 'run around' but finally managed to speak with the health educator at the college. The health educator informed her there was no formal training or resources provided for teacher trainees around HIV awareness and education. She was told they had used a programme put together by the New Zealand AIDS Foundation (NZAF) in the 1990s but it was outdated and often teachers had to find and use their own resources. The most alarming discovery from this conversation was that there was a perception HIV was no longer an issue anymore and it was not so bad because it was treatable. "It was shocking, they are not even thinking about it" the woman concluded (Participant, personal communication, September 17, 2008).

The woman who contacted Family Planning reported she had discovered Family Planning, together with public health nurses, did go into schools wherever they were allowed. Family Planning pointed out schools had different policies around Sexual Health Education which often needed to be approved by the Parents and Teachers Association (PTA) of each school, who often did not approve of sexual education around HIV. She also mentioned some schools, especially strict religious schools, might not always allow Family Planning to visit and give sexual health education in their schools. On discussing resources, the contact at Family Planning explained while there was a new resource recently produced by NZAF, they did not use it and Family Planning were keen to produce a new resource (Participant, personal communication, September17, 2008).

The same woman who contacted Family Planning also contacted someone at the Ministry of Health (MOH) who suggested she get a copy of a report done by the Educational Review Office (ERO) on 'The Teaching of Sexuality Education in years 7 to 13'. A copy of which could be downloaded from the Educational Review Office website. The person from the Ministry of Health did mention resources for schools were scarce and generally outdated (Participant, personal communication, September 17, 2008).

The ERO report was downloaded from the ERO website and copies were given to each of the participants in the inquiry group (ERO, 2007).

The other two women did not come to this session so there was no feedback on their actions.

Much discussion was generated as a result of the feedback from the actions and there was considerable focus around resources, in particular the booklet called 'HIV and AIDS: What are they? A beginners guide' produced by the New Zealand AIDS Foundation (Smythe, 2007), which was the prompt for the next action.

Everyone in the group unanimously said they felt the booklet, especially the cover, looked scary and consequently fed into the stigma surrounding HIV and AIDS. One woman suggested reading the booklet as a person living with HIV might make a person feel they were 'nasty and bad', as it was how the virus was being portrayed in the booklet.

Three members of the group had at one time worked as health professionals and all commented they would not even pick up the booklet because it looked so distasteful.

It was noted that Family Planning had said they did not use the NZAF booklet. The Ministry of Health did not use the booklet and most other agencies approached in the search for resources during the first action phase, did not use the booklet (Participant, personal communication, September 17, 2008)(Participant, 17 Sep 2008)(Participant, 17 Sep 2008)(Participant, 17 Sep 2008)(Participant, 17 Sep 2008)(Participant, 17 Sep 2008)(Participant, 17 Sep 2008)(Participant, 17 Sep 2008)

The women then chose as their next action to show the booklet to their children and/or youth members of their extended families for feedback. One woman was to contact the New Zealand AIDS Foundation to clarify exactly who the target audience for the booklet was. The women also undertook to read the ERO report as another action.

Once again the session ended with a summary of the mind-maps and reflection of the inquiry process.

While at the end of the second session it appeared a *Dionysian* culture was beginning to emerge, by the end of the third session however an *Apollonian* culture, with its more rational, systematic, controlling approach between reflection and action was materializing, with each refection phase being used to think about the last action phase which was then used to decide the next action (Heron, 1996).

6.2.4   Session Four

Once again the session started with a check-in to bring the group together. Discussions then lead into the reporting back of actions taken over the week around the NZAF booklet.

Results were surprising. One woman showed the booklet to her friend's two teenage daughters aged 17 and 20. Both the girls felt overall the booklet was great. They liked the illustrations, the colour schemes and the fonts but did feel the cover was a bit dark. Both the girls said they could relate it was the 'bug' which was nasty and not the 'person' with the virus, i.e. the bug was separate to the person. They did however feel some aspects of the booklet were difficult to understand and at times even conflicting (Participant, personal communication, September 24, 2008).

Overall, after reading the booklet the girl's views were that people living with HIV were normal people and they did not find HIV disgusting. It would appear for these two girls the booklet was effective (Participant personal communication, September 24, 2008).

Another woman showed the booklet to her 13 year old daughter. The daughters first words on seeing the booklet were, "Yuck, the drawings are not positive, they look bad and nasty". She also commented *"Does it need to have AIDS on the cover?",* but overall she felt the information in the booklet was good (Participant, personal communication, September 24, 2008).

In a personal email correspondence The New Zealand AIDS Foundation, who produced the booklet, explained the target audience for the booklet was for schools, generic mainstream audiences, libraries (not gay men, African communities, those living with HIV or health professionals) (Rachael Le Mesurier, personal communication, September 20, 2008). Apparently the intention was to make HIV scary because it was felt people, particularly youth, did not seem to think HIV was a big deal any more, but the booklet was also intended for health professionals working in the field of sexual health

Other women in the group had not been able to get feedback in the time frame of this action phase of the collaborative inquiry so it was difficult to come to any conclusive decision over the effectiveness of the booklet.

A point raised was, considering the booklet was supposed to be targeted at young people, then the language was not particularly 'youth friendly', for example phrases such as 'sexual transmission', 'precum', 'universal precaution'. Even the opening sentence of the booklet which was an attempt to define HIV, "This virus belongs to a group called

Retroviruses, which work by invading the genetic material of cells within your body" (Smythe, 2007, p. 2), was felt to be incredibly complicated and could even stop people from reading any further (Participant, personal communication, September 24, 2008.

It was suggested the language of the booklet would be more appropriate for people working in the medical profession however the illustrations were not. The group felt the booklet may have been trying to reach too many different audiences (Participant, personal communication, September, 24 2008).

Regardless of the target audience, it was generally felt by the group that by trying to make HIV scary, this only continued to feed into the stigma surrounding HIV, and as all of the women in the group did not like it, they felt most people living with HIV would probably feel the same. Even though it was recongised, people living with HIV were not the target audience, there was some concern a booklet which was potentially offensive to people living with HIV should be produced at all, especially from an organisation such as the New Zealand AIDS Foundation (Participant, personal communication, September 24, 2008).

It was interesting to note how the women in the group did not like the booklet yet the three young people (youth), the intended target audience; all felt the booklet was acceptable.

It is worth pointing out the mother of two of the girls who gave feedback on the booklet, was a nurse, who had a friend who was living with HIV (although the daughters did not know this), and the girls had grown up being educated on HIV by their mother. The third girl who gave feedback on the booklet had a mother who was HIV positive so had prior knowledge of HIV and may have felt an element of protection towards her mother which is a common phenomenon highlighted by Hoffman, Murphy, & Roberts (2002) in their study on the impact of stigma on children of HIV positive mothers. So in both cases it may have been due to their prior education and knowledge about HIV rather than the booklet which influenced their thoughts on the booklet.

It may be relevant to recognise feedback on the booklet was only from girls, all of whom had prior knowledge about HIV, and that females might be more empathetic and understanding and less likely to engage in stigmatization and discriminatory behaviour (a generalization of course).

It is also important to remember, and not surprising, the women's reactions to the booklet may have been influenced by their personal bias around not being able to disassociate themselves from the virus. i.e. the virus is ugly, nasty, dirty, scary…hence so am I.

The women recognised feedback from only three girls was not a large enough sample to provide a sufficient perspective and felt more feedback was required. It was proposed copies of the NZAF booklet be given to participants at the Youth Forum on HIV and AIDS for further feedback and this feedback be presented to the New Zealand AIDS Foundation. It was also suggested the Youth Forum might consider designing an information booklet themselves and that Positive Women Inc. would follow up on these proposals (Participant, personal communication, September 24, 2008).

Unfortunately the wrong copy of the ERO report on 'The Teaching of Sexuality Education in years 7 to 13' (ERO, 2007) had been copied. By the time this mistake was noticed and copies of the correct report sent out there was not enough time for the women to read the report in detail before session four. However the overall feeling from the group was that more needed to be done in schools to improve the standard and quality of sex education and in particular around HIV, for both the students and the teachers. The group agreed they would like Positive Women Inc. to pursue this issue further as they felt it was a very disturbing and important area of concern (Participant, personal communication, September 24, 2008).

During the session it was identified that the women in the group kept referring to themselves as *being* HIV, rather than saying "I *have* HIV". This was a significant moment for the women as they acknowledged rather than seeing themselves as separate to the virus they appeared to take on the persona of the virus which may have explained their reactions to the NZAF booklet. This lead to a great deal of discussion and the final and probably the most significant action for the women, which was to think of a new terminology with which to refer to themselves in regards to being women living with HIV.

Session four concluded with a summary of the mind-maps and reflection of the inquiry process. It was decided as session five was to be the last session, besides thinking of possible new terminologies, no other actions would be undertaken over the next week as session five would be mostly dedicated to reflecting on the overall project, its outcomes and to closure.

6.2.5   Session Five

The session started with the usual check-in and was followed by discussion on the last action around finding a new way of identifying as a person (woman) living with HIV. Some suggestions were; 'I am a woman living with HIV', 'I am living with HIV' or 'I am living with the HIV', but none of these felt right.

When saying 'living with the HIV', one women said she felt the need to add the word virus to the end, i.e. 'I am living with the HIV virus' however this would mean a duplication of the word virus as the 'v' in HIV stands for virus.

Another suggestion was to say 'I have the HI virus'. The women found this amusing, waving their hands as in a greeting and said 'hi', which creating some laughter however in the end this still did not feel comfortable. It was recognised there would probably need to be quite a large paradigm shift to enable space for new terminology to be accepted.

Once again, due to time constraints, no resolution was made in regards to this action however all the women were determined to continue to think of new terminology with which to identify themselves. Already in the short term the women were referring to themselves as 'living with HIV', highlighting that identification and discussion of the topic had already instigated a shift.

The last part of the session was spent acknowledging this would be the last time the group would be together in this context. The women talked about how it had felt being part of the project and their thoughts on the process of doing a co-operative inquiry. They reflected on any personal outcomes as a result of being involved in the inquiry and discussed what they would like to see 'happen next' in relation to actions and outcomes which had come about (but not completed) as a result of the inquiry.

A key component of co-operative Inquiry is about personal transformation and while none of the women identified anything 'life-changing' had happened for them, all of the women did however comment on how it had been a positive experience to be able to talk about things and commented on how safe they had felt. "I will miss the meetings" said one woman, "they (meetings) have been valuable to me as a participant" (Participant, personal communication, October 1, 2008).

Another woman said. "I have spoken about things I have not spoken to anyone about". While another said. "It (inquiry process) is far more constructive than a support group" (Participant, personal communication, October 1, 2008).

One woman commented "I hadn't realised how much I needed something like this, (it) makes me feel stronger in the world, not alone" (Participant, personal communication, October 1, 2008).

Another said. "It's been really good and very safe. I was reluctant to come into HIV buildings in the past. I am really grateful for the whole process; it has been very positive and thought provoking" (Participant, personal communication, October 1, 2008).

"I feel like we have achieved something", said another woman (Participant, personal communication, October 1, 2008).

The women unanimously felt there would be great benefit in Positive Women Inc. setting up co-operative inquiry groups as part of its operations. Both because of the actions involved which would give women living with HIV a feeling they were doing something proactive and constructive and because of the personal transformative nature of the process which would help to instill women with a sense of confidence and greater self worth as well as a sense of achievement.

Lunch was provided at the end of this session as a way to close the project and each woman was given a small bouquet of flowers as an expression of appreciation for their participation.

6.3   Summary

The topic for this inquiry was quite complex and ideally needed 3-5 weeks for participants just to discuss their feelings and experiences of stigma and what this meant for each of them before starting on the action phases.

Considering the time frame there may possibly have been too many aims. If the aim had been more focused, for example, "What can we, as women living with HIV, do to reduce the stigma surrounding HIV?', this would have been more specific and easier to put actions to. However there probably would not have been as much depth to the discussions.

With only five weeks there was some pressure to get the group involved in actions perhaps sooner than they were ready. In this regard it was difficult not to put on my 'researcher's' hat and from time to time I did prompt or guide the group to start thinking about possible actions. This was done subtly and I do not think it was noticed nor damaged the inquiry process, but I was conscious that I did this from time to time.

Even when actions were decided and undertaken, once again the limitation on time meant most of them were not followed through to a significant conclusion, although the group did decide the unfinished actions would be handed over to Positive Women Inc. to follow up, which in itself was an action.

Undoubtedly had the inquiry run over a longer period of time there would have been more conclusive outcomes and in that regard co-operative inquiry as a research methodology, may be better suited for a PhD where the inquiry sessions could run over a longer period of time rather than a Masters Degree, but even though the time frame for this inquiry was short, overall the aims of the project were achieved.

It was evident by what the women said they felt a sense of satisfaction and empowerment in undertaking the actions they did.

It is often common for researchers to undertake a research method which they themselves prefer or are more comfortable with (Davidson & Tolich, 1999). This was correct in my case. I liked the idea of 'co-participants' working together, discussing, reflecting, and doing something collaboratively. No vying for leadership, no power imbalance, everyone equal (in theory anyway). Using co-operative inquiry as the research method for this project probably said more about me than possibly being the most practical and best methodology for this research especially as adaptations needed to be made which deviated somewhat from the pure form of co-operative inquiry. However, I believe it was acceptable to make adaptations to the process as the overall integrity of the project was still maintained.

Raising awareness of HIV for the purpose of both HIV prevention and the reduction of HIV stigma and discrimination amongst youth and teachers was a key concern for the women and most of the actions focused around this.

It was interesting to observe how the culture and frame-work of the inquiry progressed. At times these were not consciously thought out, by that I mean, the women did not consciously ask, will we be doing an 'inside or an outside inquiry' or will it be 'open or closed', which indicated a very natural process was taking place which did not require directing or instructing. It was interesting to see how the women instinctively worked together when given the freedom to be equally heard, listened to and respected.

7 Reflective Analysis

7.1 Introduction

As has already been identified, a true co-operative inquiry does not necessarily lend itself to analysis as there is no defined hypothesis to prove or disprove. The process is fluid and discussion enabling of in-depth exploration. Co-operative inquiry is more about reflection than analysis, undertaken by the participants, not the researcher. However in order to comply with the academic requirements for this thesis, an analysis has been done as an analytical reflection as a compromise to stay somewhat true to the process of co-operative inquiry and ensuring the academic requirements are also met.

This reflective analysis may appear to be mostly from a 'researcher's perspective' as it analyses and critiques occurrences and outcomes compared to findings identified in the literature review. To counterbalance this, quotes by the participants have been used as much as possible to ensure the participants voices and meanings are present and maintained as well as being used as evidence to support the analysis. This process is compatible with the opinions of Straus and Corbin (1994) and Charmaz (2000) who argue that both an evolved and constructivist approach to ground theory allows for interpretation by the researcher through the previous review of literature and if the 'raw data' is maintained as much as possible.

As the relationship between the researcher and participants in this project was that of co-subjects, working together from a shared understanding and experience, it is hoped a reasonably accurate analysis has been reached. However it needs to be recognised the analysis may not entirely always reflect the point of view of those who participated in the inquiry as participants did not have the benefit of reading and having a literature review to compare their reflections with.

Even though the women had agreed to be part of the study, not everyone was clear on what 'stigma' really meant. Subsequently the group spent considerable time during the first session discussing what 'stigma' meant and how, if at all, it affected them. As a result of this discussion and also as the inquiry sessions progressed some common themes began to emerge, these where; shame, a fear of being judged, fear of rejection, lack of self esteem, tolerance of unacceptable behaviour, especially by partners, the internalisation of stigma, fears around disclosure and the lack of support. Each of these are discussed in more detail as follows.

7.2 Shame and fear of being judged

7.2.1 Inquiry reflections

The fear of being judged was initially so profound for some women they felt they could not even tell their family members when first diagnosed because of their deep sense of shame and embarrassment.

> Being a woman with HIV people straight away think you must be promiscuous or a prostitute or a drug addict, said one woman (Participant, personal communication, September 3, 2008).

Another woman said,

> I feel a huge sense of shame, people make assumptions, and I don't like it when people think they know me and then try to put me in a box. They don't know me or the situation and have no right to judge me. I hate being put in a box (Participant, personal communication, September 3, 2008).

Someone commented how when she was diagnosed, for many years she hadn't made any new friends for fear they might find out she was living with HIV and judge her. "I didn't let people know me to protect myself" she said (Participant, personal communication, September 3, 2008).

One woman told how when she was teaching, some of the students in her class had commented how people living with HIV should not be allowed in the workplace as it was too dangerous.

Another woman shared how when she was a school nurse, the attitude of some of the 16-17 year old boys at the school was that;

> People who have AIDS (are bad) and should be sent away to live on an island She questioned, Where did they get these ideas from (Participant, personal communication, September 3, 2008).

Someone responded, "Society has a hiccup with sex. Sex is a no-no" (Participant, personal communication, September 3, 2008).

And someone else added,

> It's as if it's wrong to have sex and if you do, people make judgments about you, that you are promiscuous or a slapper (Participant, personal communication, September 3, 2008).

One woman said;

> I guess I did sleep around a bit. Looking back I can see I did this because I was searching for love and sex was the only way I thought I could get someone to love me. Then when I was diagnosed with HIV, I thought people would say that it was my own fault for sleeping around and that I got what I deserved, so I didn't want anyone to know because I felt ashamed (Participant, personal communication, September 3, 2008).

Someone commented how 'sleeping around or being promiscuous' was in itself a misconception.

> You don't contract HIV from sleeping with a lot of people she said. It's not about the number of partners you have. You don't get HIV because you have sex with a lot of men, it only takes one (Participant, personal communication, September 3, 2008).

A discussion on the ambiguous ways in which sex is portrayed followed. Sex is considered a 'no-no', yet pop music and TV programmes constantly portrayed sexual images or storylines including TV soaps such as Coronation Street and Shortland Street, which were aired at family viewing time. Yet society, was not willing to acknowledge sex happened in everyday life and there appeared to be something shameful about having sex.

One woman told how she noticed her children had not told anyone about her HIV status, even thought she had not told them they should not tell. She felt this was possibly linked with a sense of shame especially as the children went to a Catholic school, but that this was more around sex than HIV. "Your good mother has HIV...that means she must have had sex" (Participant, personal communication, September 3, 2008).

It was also felt the children probably had not told anyone in an attempt to protect their mother from being judged and from fear of possible discrimination. She followed by saying even though she had not told her children, not to say anything, in a way she was glad they hadn't. She said;

> There seems to be such ignorance about how you get it (HIV), kids at school would probably think they will contract it from my children (even though her children do not have HIV), (Participant, personal communication, September 3, 2008).

Another woman shared how she had asked her 14 year old son not to tell anyone about her HIV status as she was afraid he might be ostracised by his friends at school. However she felt by doing this she had put the burden of her secret onto her son which

he then had to live with in relative isolation. Her son did keep the secret and it was felt that once again, keeping the secret was probably more about protecting his mother than about protecting himself. Her son did eventually tell some of his friends when he was 20 years old

> His friends were older and more mature and they had known me for many years by then so were less likely to judge me and as it was, they were all fine with both my son and me. But I think if it had been the first thing they had known about me it might have been a different story because they would have made judgments about me without knowing me first (Participant, personal communication, September 3, 2008).

It was generally accepted by the group that comments such as those made by the 16-17 year old boys and in general the attitudes of teens were more of an 'age thing', but it highlighted the lack of understanding there was about HIV by young people.

While on the whole it was agreed generally New Zealanders were relatively open-minded and accepting, (although there are always some bigots), the main problem seemed to be that there was a huge lack of knowledge and understanding about HIV in New Zealand.

One woman said she thought the judgments and stigma around HIV existed predominantly because "people (society) won't listen or are not educated so we have a big battle as people are ignorant" (Participant, personal communication, September 3, 2008).

It was felt this ignorance was the principal factor contributing to the misconceptions around HIV and AIDS resulting in judgments (stigma) and discrimination and that the judgments (stigmatisation) made by society compounded the sense of shame for those living with HIV, even if the judgments being made were not true.

7.2.2   Reflective Analysis

While not often verbalised, the feeling of shame was however unmistakably evident. Possibly some of the women did not recognise what they were feeling was 'shame' yet the women identified quite readily with a fear of being judged.

Evans (1994) defines shame as, 'a feeling of being unworthy, inadequate, or defective' (Evans, 1994, p. 4), which are common metaphors used by society to define stigmatised populations, especially those living with HIV or AIDS (Sontag, 2001). However while shame is often connected to a fear of being exposed (judged) by *others* it is also an

'internal reaction' and it does not always require anyone else to be present to bring about feelings of shame.

Women are particularly vulnerable to shame as a consequence of being regarded as second class citizens in a male-dominated society and from centuries of cultural devaluation and oppression, resulting in the belief there is 'something wrong with us'. This is particularly evident in regards to HIV where women are often seen to be the transmitters of the virus or stereotyped as being either promiscuous, sex-workers or intravenous drug users (Barton et al., 2006; Bennett, 2007; Gibson & Rohleder, 2006).

A woman's sense of self esteem is largely reliant on being connected to others in a meaningful way so it was significant to notice that the women were strongly fearful of being judged, or rather being wrongly or misjudged (Evans, 1994).

What was evident throughout this project was that none of the women had anything to be ashamed of and while the women appeared to have a logical understanding of this, I believe they did in fact suffer from the effects of shame and this sense of shame originated more from the social stereotypes and stigma associated to being a woman who has HIV. One might also argue, from a feminist perspective, that this shame may also be linked to generations of both female and sexual oppression (Richardson & Robinson, 1993)

While it might be easy to blame men for this, women also engage in devaluing and disempowering behaviour to each other (and themselves), sometimes intentionally and often in ways they are unaware of (Gibson & Rohleder, 2006).

An element of denial around acknowledging shame may also have been present. By acknowledging shame the women may have felt there was a need to accept a degree of responsibility and it may have been easier for the women to identify with the fear of being judged as this was something outside of themselves and possibly something they felt they could control by hiding their HIV status from others (Goffman, 1959) while shame is something which can be generated both externally and internally (Evans, 1994).

Fear of being judged also facilitates a thinking that 'others' lack an understating or are uneducated about HIV (which they undoubtedly are) but once again this allows those affected by HIV to separate themselves from the stigma (shame) attached to HIV.

Reflections by the women about why their children had not disclosed their HIV status, would appear to agree with other studies done on the subject where it was found children

instinctively did not tend to disclose their mothers HIV status to friends, regardless of whether they had been asked to tell or not (Barton et al., 2006: Hoffman et al., 2002).

There was discussion as to whether the children might feel an element of shame in disclosing such information but overwhelmingly it was felt this silence was probably more of an attempt to protect their mothers rather than being ashamed or worrying about the impact on themselves which was also seen in a study done on 'Children carrying the secret of their mothers' HIV+ serostatus' by Hoffman et al., (2002).

This protectiveness was reciprocated by the mothers who felt the need to ensure a sense of normalcy be maintained (through non disclosure) to protect their children from the impact of people's reactions and judgments (Abell et al., 2006) and that the sense of (unacknowledged) shame was more the burden of the mother.

7.2.3   Conclusion

Shame and fear of being judged are difficult to separate which is why they have been identified and written about as one theme, even though they are two separate reactions.

In my conclusion I would suggest if one has a fear of being judged, this will generally be accompanied by a sense of shame. There may also be an element of denial (or lack of understanding) around shame as it might suggest a perception of responsibility. I am not suggesting there is, just that there might be a possible perception whereas judgments (made by others) are totally external which allows an element of control which may be easier for the women to accept (i.e it is them not me), yet some people do self judge and self blame. This is a very complex issue and unfortunately was not in the scope of this inquiry to investigate, but would be an interesting topic for a future inquiry.

7.3   Disclosure

7.3.1   Inquiry reflections

Two of the women in the group were very open about their HIV status; both being involved in HIV advocacy, education, awareness and prevention campaigns.

Two of the women, had told their immediate family and close friends and children, otherwise they were very guarded and protective over whom else they told.

The four women who had disclosed the most had all been diagnosed for more than 13 years.

The woman who had told the least number of people, (only her mother and ex-husband), had known of her status for a shorter time (4 years). This woman was also a new immigrant to New Zealand and besides her son, had no other family in New Zealand which may have contributed to her not telling many people. While this woman had not yet told her son, she thought he probably suspected as she took her medication in front of him, but he never asked what the medication was for. She felt he was probably afraid to ask because he suspected what the answer might be.

Another woman shared how when she finally told her two sons, they too had already worked it out but interestingly had not suspected their father was also HIV+.

Breakdown of disclosure questions from demographic form.

Participant	1	2	3	4	5
Age	32	37	47	48	51
Number of years lived with HIV	15	4	13	15½	20
Mother	Yes	Yes	Yes	Yes	Yes
Father	Yes	n/a	Yes	Yes	Yes
Brothers & Sisters	Yes all	No	Yes all	Yes all	Yes all
Children	n/a	No	Yes all	n/a	Yes
Close Friends	Yes	No	Yes	Yes	Yes
GP	Yes	Yes	Yes	Yes	Yes
Dentist	Didn't answer	No	Yes	No	Yes
No-one	n/a	n/a	n/a	n/a	n/a
Other	Is public about HIV status	Ex-husband	Didn't answer	Some health professionals but not physio	Is public about HIV status

Figure 8: Participant Disclosure Information

There were conflicting opinions around disclosure. Some women felt HIV was a personal issue and did not think it was necessary to tell anyone except maybe people who they were close to or people whom it might affect. However it was unanimously agreed that a person should not have to live in fear of what might happen if it were found out they were a person living with HIV.

Some women were even reluctant to disclose to health care professionals. One woman shared an experience of a recent visit to a health professional. It was her first visit to this health professional and while she realised she would need to disclose her HIV status, she was hugely apprehensive, she said;

> I built it up to be a big thing because I feared his reaction but when I did tell him he didn't react, it wasn't an issue (for him) at all (Participant, personal communication, September 3, 2008).

She said his acceptance had surprised her and she could not understand where her fear came from because after all, he was a health professional. "It (fear) must come from somewhere?" she said (Participant, personal communication, September 3, 2008).

Another woman told how she had done an educational talk at a school where she had shared she was living with HIV and said, "Some of the people, especially the kids, didn't believe I had HIV as I didn't look sick" (Participant, personal communication, September 3, 2008).

One woman commented;

> Prior to totally 'coming out' (being public), I was petrified for many years about people finding out I had HIV. I kept my status a secret from everyone except my family and a few close, trusted friends yet when I went public (for awareness and educational purposes) I was so surprised because I have not experienced any discrimination or been rejected by anyone. The reality was nothing like the fear I had imagined for all those years (Participant, personal communication, September 3, 2008).

Another woman commented,

> I don't test it out so I don't know the reality of stigma and have not experienced any discrimination. I only told a few people who I felt it would be safe to tell and have never experienced being rejected but I have spent many years being afraid of people outside of this close circle knowing and this has probably been more about being judged than being rejected (Participant, personal communication, September 3, 2008).

A woman who had effectively always been open about her status since being diagnosed 15 years ago, explained how she had experienced rejection by some of her '*so called friends*' in the beginning but added it had shown her who her true friends really were. She had only been 16 when she was diagnosed and it was felt the age group and lack of maturity and understanding around HIV from her peers at that time may have been an

influencing factor in their response to her. Overall though she said she had been accepted and had found no difficulty in getting a boyfriend.

7.3.2   Relationships

A common anxiety for the women was around both intimate and sexual relationships with men and the fear of disclosing and being rejected by potential partners.

One woman said,

> I haven't been in a relationship in 14 years. I have always been afraid that no one (men) would want me once they knew I had HIV and rather than go through that pain and hurt, I have just not allowed myself to get involved with anyone. I also could not imagine ever again feeling comfortable about having sex, even with a condom, as I would always be afraid that somehow I might pass the virus on (Participant, personal communication, October 1, 2008).

She explained as a person living with HIV she felt, "It is my responsibility to tell any potential partner straight away" (about being HIV+) (Participant, personal communication, October 1, 2008).

She believed the other person (partner) had a right to make an 'informed choice' about entering into *any* activity, with her, even kissing. Although she was aware there was no legal requirement to disclose her HIV status as long as she took precautions (wearing a condom), nevertheless she felt she had a moral obligation to disclose but because she was so fearful of being rejected she had chosen not to get into another relationship ever again.

> HIV is about sex and since being diagnosed I don't really want to have sex anymore, it's too difficult to think about. I feel like a black widow spider, contaminating my partner with my poisonous blood (Participant, personal communication, October 1, 2008).

She explained even though she worked in HIV awareness and education and was constantly reassuring other women living with HIV they would find love, and even though she believed this for them, she did not feel this would happen for her.

Another woman said she had never felt poisonous.

> I contracted HIV from a rape and can separate it out. I thought nobody would love me but actually had more than one person who wanted me (Participant, personal communication, October 1, 2008).

Another woman shared how she too had not been in a relationship since splitting from her husband.

> I could never imagine getting into another relationship. I don't have the courage to tell a man I have HIV, especially men of an older generation who still think HIV equals AIDS. I am not so much worried they will judge me but I am afraid they will reject me. I feel no man would want to be with me especially as they would always need to use a condom and most men who do not have HIV won't want to always use a condom. It's not fair as I only have a virus (Participant, personal communication, September 3, 2008).

A woman who had been married for 15 years shared. "I hate condoms" she said "but we have a physical relationship and there are different ways of loving" (Participant, personal communication, October 1, 2008).

One woman shared how she had only just entered into a new relationship with a man she had know for a long time and who had known she had HIV before they got together.

> I found someone who really loves me. I feel like a teenager. I feel so special and it has changed how I feel about myself (Participant, personal communication, September 10, 2008).

She commented how she felt this had a lot to do with the fact he had known she was living with HIV before they got together and had still wanted (chosen) to be with her anyway. However she was nervous about how her partner's children would react when they knew their father was living with a woman who has HIV.

Another woman shared how her husband too had already known her status before they started going out and in that regard she had not needed to (specifically) disclose when they started dating.

Another woman shared how she was initially concerned she would not find a man who would accept her because she had HIV, but was then surprised to have meet a man four years ago who did not seem concerned at all and they had got married. The marriage had not lasted, and while HIV did play a part in the breakdown of the marriage it was not because her (ex) husband was afraid that she had HIV.

Generally the women accepted the *fear* of being rejected was probably more powerful than the *reality* as it was recognised most of the women in the group had experienced very little rejection in relation to disclosing their status to potential partners. However it must to be recognised two women in particular had ensured they kept themselves

protected from that possibility by not getting involved in any relationship at all and a third woman had gotten into a relationship with someone who had already known of her status not long after she had been diagnosed. As they got married and have been together ever since meant this woman had not needed to disclose her status to any other potential partner.

7.3.3 Support

Everyone in the group had, through necessity, disclosed their HIV status to some health professionals and all were members of Positive Women Inc, however, everyone agreed there was not enough support in the community for people living with HIV.

One woman shared a situation.

> A work colleague of my husband was diagnosed with diabetes but it took some time for this to be diagnosed, in the mean time he was very sick, everyone thought he might have cancer. I spoke with his (the man's) partner and offered support. Lots of people where helping him and he got lots of support around him, yet when I get sick, my husband can't get the same support as he can't tell others about me as he is worried about the repercussions for himself and me. We have to hold it all in, at least you can talk about cancer in a public place. There is a huge amount of support we don't get, which makes me cross about stigma (Participant, personal communication, September 10, 2008).

Another woman commented that in her country people died because they did not want to admit they had HIV.

> People are scared of HIV. Maybe it's because HIV is in the 'dirty' category. Cancer or diabetes is 'clean. If you are sick because of HIV, while individual families are supportive and protective (it) would not be surprising if those who come to see you (friends, neighbours) don't come back again and if in hospital, people would only come to visit at the end stage to come and check to see how long you have to go (Participant, personal communication, September 10, 2008).

Most of the women in the group had told at least one, if not both of their parents about their HIV status and most had also told their siblings. While all of the women felt their families were supportive to some degree, this support was often in a cautious or hesitant sense and they all said they felt the need to appear strong for the sake of their families.

One woman said;

> My family treats me differently. They see me as being
> strong so I have to deal with it (HIV) myself. One time
> when I was unwell, I let my family know. My sister rang me
> for a week (this woman has four sisters), then nothing, it's
> like they are disassociated from me. For something else
> (another type of illness), all this support exists but no one
> rallies around me. I don't get the same help. I feel like they
> are scared of me and won't look after me. I feel shit about
> this, it pisses me off as it happens constantly in my family
> (Participant, personal communication, September 10,
> 2008).

After hearing this story the women in the group nodded their heads as if they identified with the situation and one woman said, "HIV is not spoken about, it is silent, when you have HIV you walk alone" (Participant, personal communication, September 10, 2008). To which everyone agreed.

7.3.4   Reflective Analysis

It would appear statistically, disclosure of their HIV status for women in New Zealand is not widespread which seems to be quite common in developed countries as was recorded by Marks et al., (1992) in Los Angeles where rates of self disclosure were recorded to be as low as 5.5%, significantly lower than in many developing countries where disclosure was recorded by Medley et al., (2004) to be between 16.7%- 86% (cited in Fang et al., 2006).

These differences may be attributed to the availability of social support and the management of uncertainty for people living with HIV. In countries like New Zealand, where there is access to ARV's and good medical services including counseling and established support networks there may be less inclination to disclose one's status than in places where these are not so readily available (Brashers, Goldsmith, & Neidig, 2004), so it could be concluded that disclosure of HIV might be less likely in a country like New Zealand where HIV is less prevalent.

Fears around disclosure and a lack of support often left these women feeling isolated, yet 'isolation' as a theme was not discussed, but that may simply have been a matter of language as comments such as "feeling unsupported" and "walking alone" are synonymous of isolation as a result of stigma (Sontag, 2001).

Most of the women commented they felt there was a lack of support for people living with HIV in New Zealand but this did not entirely match with what was discussed during the sessions. All of the women had disclosed to some family and/or close friends as well as

some health professionals and had generally been surprised these people had been more accepting than they had anticipated. All the women were members of a peer support network (Positive Women Inc.) but yet overall the women still felt there was a lack of support.

Similar to findings in other studies (Barton et al., 2006: Serovich, 2000), the women in this study felt even though disclosure to family and close friends had not been a negative experience this had not however always resulted in the degree of support they had hoped for. While the women acknowledged this might be because their family and/or friends did not know how to provide the required support, the result never-the-less left them feeling hurt and unsupported.

What was not clarified however was exactly what kind of support it was the women expected or what their definition of support was. From what was discussed, it appears a need for acceptance was what the women were seeking, not merely by family and close friends but by society in general. Being a minority group in a low HIV prevalent country can be very isolating especially when living with a disease as heavily stigmatized as HIV. Add to this the lack of education and understanding around HIV by the general population, it is understandable these women did not feel supported (Barton et al., 2006: Bennett, 2007: Link & Phelan, 2001).

A significant concern for the women was around disclosure of their HIV status to potential partners. This was predominantly linked to fears of possible rejection, and also to some extent around fears of being infectious. As in other studies (Barton et al., 2006: Gibson & Rohleder, 2006: Lekas et al., 2006), it was also seen how the 'perceived' fear of both rejection and discrimination often prevailed over the reality as three of the five women had all been in one or more relationships with men who were not HIV+ with little to no rejection in regards to their HIV while the other two women had not allowed themselves to become involved in any kind of partnership so did not in fact know the reality of what might happen.

It is significant to reiterate that the two women who had actively chosen not to enter into any further relationships both had children and it is not uncommon for women living with HIV, who have children, to devote themselves to their children, which often also acts as an incentive (purpose) to continue living (Barton et al., 2006: Hoffman et al., 2002: Hutchinson & Ingram, 1999) and could also be a contributing factor for not seeking new relationships.

Only one of the women (who had children) had not told her (teenage) son about her HIV, although she suspected he knew as she took her medications in front of him. What was interesting was that this woman appeared to be relatively at ease about having HIV and talked about one day wanting to speak in a public arena, in an educational capacity about HIV however she had not yet been able to disclose to her son.

It is not uncommon for women living with HIV, who have children, to try to maintain a semblance of normalcy for the sake of their children (Hoffman et al., 2002), however, this woman's son was not young so it was doubtful she was worried he might be unable to comprehend the information. And while on one hand she seemed to want to protect him from the burden of her secret, on the other hand she was open about taking her medications in front of him, almost inviting him to ask questions. There was obviously a enormous dilemma going on here as the son, while possibly guessing, may be afraid to ask in case his worst fears are realised and anxious of confronting the situation, leaving him in a state of probable apprehension and uncertainty.

Consistent with findings in the research done by Hoffman et al., (2002), of the two women who had told their children, none of the children had disclosed their mother's status to their friends, regardless of what instruction they had been given by their mothers. As with findings in the study done by Hoffman et al., (2002), the women in this study also believed the reason the children did not disclose was more about protecting their mothers than worrying about any repercussions to themselves or feelings of shame on behalf of their mothers.

Only one woman had not told more than two people of her HIV status. This woman had only been living with HIV for four years so was a relatively new immigrant with no family in New Zealand except her teenage son. Although this woman had not told many people she appeared very well adjusted to her HIV status and was keen to get involved in HIV awareness and education and talked about being 'out' about her HIV status in the near future which was contradictory to evidence found in a British study around African migrants (Burns et al., 2007), but then again she was only one woman. Considering there are just over 200 African refugee and migrants in New Zealand living with HIV (McAllister, 2009) and none of them are public about their status, it would appear overall the situation in New Zealand is similar to that in the British study.

Of the two women in this study who were public about their HIV status, one had been openly public since being diagnosed at 16, just over 15 years ago. The other woman, who contracted HIV 20 years ago at the age of 30, had only been public about her HIV

status for four years, choosing to keep her status relatively secret until after her son had grown up and would not be so directly affected which was again consistent with findings in the study done by Hoffman et al., (2002) on 'Stigma and ostracism associated with HIV/AIDS: Children carrying the secret of their mothers' HIV+ serostatus'.

In relation to the participants involved in the project, there seemed to be no real pattern in regards to either length of time since diagnoses or age as determining factors in disclosure (C. Emlet, A, 2006). However since there have been nearly 450 women diagnosed with HIV in New Zealand (McAllister, 2009) and there are currently only 8 women who are openly public about their HIV status (Bruning, 2008), and while two of the women who took part in the project were 'thinking' about being more open about their status, only 2 of the 5 women in this study were in fact open at the time of the project.

One woman had disclosed her HIV status to her employer but this was only a relatively recent development as her job involved working for an HIV support organisation (Positive Women Inc.). Prior to taking on this job, like the other women in the study, none had disclosed their HIV status at their place of work for fear of discrimination or being dismissed. This is discussed in more detail in chapter 8.4.1

7.3.5   Conclusion

All the women in the study had at some stage, since their diagnoses, displayed classic characteristics of coping strategies such as *passing*, *covering* and *seeking the own and the wise* used by people living with HIV as identified by Goffman (1963).

Disclosing one's status, whether to family, friends, health professionals, lovers or children where significant stressors for the women in the study. While not everyone had experience rejection or discrimination, most were fearful of it to some degree and had put strategies in place to protect themselves.

Apprehension and fear around disclosure to potential partners had at some stage been a significant stressor for all of the women but this *perceived* fear had generally not translated in reality.

The women with children were hugely protective of their children and attempted to maintain a semblance of normality as much as possible. There was no consistent pattern identified around disclosure to the children of their mothers HIV status as each of the women had chosen different ways of managing this which suggests it is a very personal and individual process and there is no right or wrong way.

This study supports prior research on the need for psychological interventions for women with HIV and identified social support as an important external resource for improved psychological change, quality of life and over-all life satisfaction. While Goodry (2005) suggests women perceive friends as more supportive, it was however evident in this study that family support was considered very important.

A strong and consistent association between social support, superior self concept, and self esteem was identified but it was recognised that attempts at achieving this would require a multifaceted approach and suggests support groups may be helpful. Further research might consider exactly what forms and sources of HIV related support are most helpful.

Fear of discrimination at work and status in the community were significant factors for all the women in the study, highlighting both societal and internal aspects of stigma which are discussed in the next chapter.

7.4   Internalised Stigma

7.4.1   Inquiry reflections

An observation made during session four highlighted how when talking about themselves in relation to HIV, the women in the group often referred to themselves by saying, 'I am HIV+'.

As one woman said,

> By saying 'I am HIV+' I am taking on the persona of the virus. I am saying 'I am' the virus, rather than being a person who has or is living with the virus (Participant, personal communication, September 10, 2008).

For some of the women, this was the most significant realisation to come out of the whole project. While this has been discussed to some extent in chapter 7 as one of the actions undertaken during the inquiry, due to the impact this discovery had on the women it is being mentioned again in this chapter but this time in the context of internalised stigma.

Much discussion was had on this topic as the women realised, and acknowledged, they did not see themselves separate to the virus but instead felt 'they were the virus'. The women believed this was directly linked to stigma and was an indication of how they themselves had subconsciously and inadvertently internalised stigma.

A comparison was made to people who have cancer, "People with cancer don't say, I am cancer, they say, I have cancer" (Participant, personal communication, September 10, 2008).

One woman commented, "We think HIV and us are one" (Participant, personal communication, September 24, 2008).

"So how *do* we name it to ourselves", someone queried (Participant, personal communication, October 1, 2008).

"It is important for me to say 'I have the HIV virus'. It takes the power out of it" another woman responded (Participant, personal communication, October 1, 2008).

Someone else commented, "It doesn't have to have so much power. It's only a virus and I give it the power (Participant, personal communication, September 10, 2008).

Another woman responded, "It's not just a virus, it attacks everything in life, it influences and changes things" (Participant, personal communication, September 10, 2008).

One woman shared how even after 20 years of living with HIV and knowing all about how it is transmitted and even though she was constantly involved in HIV awareness and education in the community, she still had some fears about accidently transmitting HIV to someone else She explained how if her son asked for a bite from something she was eating, like a chocolate bar or biscuit for instance, she would break a piece off from the end where she had not yet eaten. She also explained how she would get a clean spoon rather than share the spoon she had been eating with, even though she knew there was no way her son would contract HIV through either of these means.

Another woman shared how at work, even though people didn't know she had HIV, she took her own cup to work and made sure no one else would drink from it. She said she did this in case anyone ever found out she had HIV and then she would feel she could justify she had not put anyone at risk because she had been careful, i.e. used her own cup. Interestingly, her work colleagues noticed she had brought her own cup and mentioned to her she did not need to because there were plenty of cups in the staff room. Her response was to explain it was a special cup to her which is why she brought it to work. The same woman also shared how she would not even share a cup she had been drinking from with her son.

Someone else explained how she had felt huge stress working as a nurse when she found out she had HIV. She was fearful of people at work finding out and was also fearful

of accidentally transmitting HIV to someone at work, even though she understood the reality of that to be highly unlikely.

> It affected how I felt about nursing. What would people think (and do) if they found out? I won't do nursing now (Participant, personal communication, September 24, 2008).

Another woman explained how she had got some glass in her foot once and a friend, who knew of her HIV status, had come forward to help remove the glass. She said she almost shouted at her friend not to touch her. "I worry about passing it on to others" said one woman "Where do we get this sense of infectiousness?" said another "What is this about? This (examples discussed) is not how you contract it (HIV)" she continued. "I think it's more about what I am feeling inside" said the first woman. "I think it comes from' out there' (society) but I internalise it" commented another woman (Participants, personal communication, October 1, 2008). "It's like the knowledge and the emotional connection is mixed together and we carry what others might be thinking" (Participant, personal communication, October 1, 2008).

Another woman said, "It angers me that society creates stigma that everyone believes and which leads to discrimination" (Participant, personal communication, October 1, 2008).

The question was asked 'how do you take stigma away?' and someone commented, "We only have stigma because people are not educated and this education can only happen through us" (Participants, personal communication, October 1, 2008).
While another woman said;

> Maybe the first step is to define ourselves. Maybe I need to focus on what it means to be me rather than being HIV+ (Participant, personal communication, October 1, 2008).

Someone else commented, "I question how much (stigma) is out there and inside me?" (Participant, personal communication, October 1, 2008).

The women acknowledged they had internalised much of the stigma around HIV and also conceded the reality of their feared or perceived reactions from people, if it were known they were living with HIV, may not be as bad as they thought, yet most of the women were not prepared to test this out. "Once it's out, you can't take it back" (Participant, personal communication, October 1, 2008).

While another woman said, I'm not ready for taking stigma away, it's a big step"
(Participant, personal communication, October 1, 2008). No further elaboration or
discussion was had in relation to this statement so it is unclear what was meant by this
comment.

7.4.2   Reflective Analysis

Unfortunately, but through necessity, for people to live together in social order requires
there be some form of shared meaning or understanding and this shared meaning
comes from the way people interpret and then label their perception of reality. Often
people can become helpless victims of interpretations or labels put on them by others to
such an extent their social identity can become imposed on them even against their will.
This can be seen in people who are affected by stigma. Sometimes the process of
labeling (stigmatising), especially when it is constantly and determinedly being applied by
others, can be so strong it can affect even those who have been labeled incorrectly.
Regardless if the label completely contradicts what a person actually thinks of
themselves, the affects of labeling (stigmatising) can be so profound that the person
being labeled will start to doubt themselves and internalise the labels others have applied
to them (Jones, 1991).

Nyblade (2006) adds that internalised stigma requires a level of acceptance by the
stigmatised person/s that what is being said (or feared) by society, is true (Nyblade,
2006) and whether the label is correct or not has no relevance as the impact of the
constant labeling will eventually result in the collapse of the persons own self image. It is
through this constant application and the reactions of others to its existence which makes
it become true for both the labeler and the labeled (Jones, 1991).

This was evident with the women who took part in this project. Each and every one of the
women was affected almost by a sense of bewilderment, dismay and fear that if it were
to be known they were HIV+, they would be labeled, judged, stigmatised and
discriminated against. Prior to their HIV diagnoses these women had considered
themselves to be 'ordinary, normal' citizens and so had struggled immensely to come to
terms with being perceived as 'lesser' members of society. And while, logically none of
them really believed this, however all of them, to some extent had internalised the
stigmatising labels attached to being a woman living with HIV and so felt ashamed and
ostracized.

Sontag (2001), like Jones (1991), believes stigma is compounded by the use of
stigmatising metaphors and the public perception of stigma. This 'social stigma' is

subsequently internalised to the point where those affected subconsciously take on the social projections of stigma and believe themselves to be as they are portrayed by society (Sontag, 2001: Goffman, 1959: Link & Phelan, 2001: Jones, 1991).

While Jones (1991) believes a person's self image is largely shaped by the way they *think* other people interpret their behaviour (whether the interpretations are correct or not), he argues however that people are not just reactive creations of others (Jones, 1991).

Hollway & Jefferson (2000) suggest when a person is attacked or threatened they are capable of creating 'defenses' against the threat/s by becoming actively involved in managing their identity and protecting themselves against the uncertainties associated with a spoiled identity. For example, Goffman (1959), believes humans use props such as the clothes they wear, the way they walk, talk and do their hair as well as the type of house they live in or even the type of car they drive which can be used to present an image that people want to portray but which may not in fact be correct. This is exactly what people affected by stigma do while in the 'Passing and covering phases'. That is, they manage the information they give to others thus retaining some perceived control around how they *want* people to see them (Goffman, 1959).

Interestingly the main defense used by three of the women in this study (at the time of the study) appeared to be that of '*passing'* and '*covering'* which merely worked to reinforce the negative and isolating effects of stigma. However, these strategies were probably outweighed by the perceived benefits as identified by (Anderson& Holliday, 2004: Goffman, 1959).

We can see, as did Gibson & Rohleder (2006) in their study on women in South Africa, the social constructs of stigma are so profound that once a woman has been diagnosed as being HIV positive she unconsciously absorbs these negative constructions, through language and labels of HIV related stigma into her own sense of self worth. This was particularly evident in this study when the women realised they spoke of themselves as "being HIV+" or "I am HIV" and by doing this they took on the persona of 'being the virus'. Link & Phelan (2001) identified this as a common phenomenon for those affected by stigma using the example of how people often label those affected by schizophrenia as 'schizophrenics' rather than being described as a person who has schizophrenia. Thus making the stigma something '*in the person'* rather than a label others '*attach to a person'* (Link & Phelan, 2001)*.*

This was a very significant discovery for the women and something they had not been aware they were doing. Interestingly it was the support person, a person not living with HIV, who pointed it out which is an indication of how much this had become an ingrained construction. Once the women became aware however, there was considerable discussion around reconstructing a new terminology or a new way of identifying themselves and this became an important action point of the inquiry.

Even though the women believed how they identified themselves in regards to HIV contributed significantly towards the way they internalised stigma, they were not however able to construct a new terminology during the timeframe of the inquiry. There may need to be a larger paradigm shift by both society and those living with HIV for this to change, reinforcing the real depth and power of both external and internalised stigmatisation. It is very significant to mention however that once the women became aware of how they had been identifying themselves, from that point on they began to refer to themselves as "women living with HIV".

One might question if saying "I am HIV+" is in fact suggesting the person affected then takes on the persona of the virus. Does it not actually mean "I have tested positive for the Human Immunodeficiency Virus", which is actually another way of saying, "I have the Human Immunodeficiency Virus"? It appears the process is much more complicated and internal as was evident from the women's reactions to the HIV booklet produced by NZAF (Smythe, 2007), when they were unanimously uncomfortable with the virus being portrayed as evil and ugly as they instinctively felt this reflected who/how they were.

All the women were aware of how HIV is, and is not, transmitted, yet each of them expressed a degree of what appeared to be 'irrational fear' about transmitting HIV to others in ways they rationally knew were not possible. As well as knowing the educational information on HIV transmission each of the women had practical experiences such as being in relationships and/or brining up children, or working (as nurses, HIV educators), where no transmission of HIV had occurred, so why then were these women still so anxious about something so irrational?

To some extent one is able to understand the manifestation of internalised stigma when judgments are based on assumptions made from a moral perspective. Yet the overwhelming irrational fears expressed by the women in this project in regards to accidently transmitting HIV through casual contact, which is highly improbable, is a curious phenomenon as the unlikely hood of this has been backed by significant scientific evidence.

Ironically the very message these women want to get across to society to alleviate fears around HIV transmission and stigma were the very fears they held themselves. Were any of these women to hear (non HIV+) members of the community suggest HIV might be transmitted through sharing food or eating utensils they would no doubt be appalled and possibly even offended, yet each and every one of them held some form of irrational fear of their own.

While there was literature on irrational fears around HIV transmission by *non* HIV positive people (Gelman, 1993: Nyblade, 2006), I was not able to find any literature on irrational fears around transmission by people living with HIV. This may be a matter of language as it appears what might be defined in non HIV positive people as 'irrational fears', may be defined in those living with HIV, as 'internalised stigma'.

Although the women appeared to have 'irrational fears' around transmitting HIV through casual contact, Fang et al. (2006), identified there was also a significant '*perceived fear*' by those affected, of what others might *think and do* if they were known to HIV+. Maybe this is the real issue rather than the (irrational) fear of transmission. We saw a glimpse of this in the situation with the woman in this study who took her own cup to work. Another example was the ex nurse who explained how having HIV had affected the way she felt about nursing to such an extent she had left her job. In both these cases the women had also expressed concerns about 'anyone at work finding out', they had HIV.

Even the women in this study who were public about their HIV status did not seem able to overcome their irrational fears around (possibly) transmitting HIV, if that is truly what the fear was about, which highlights how stigma is so ingrained through society and culture that its effects cannot be overcome through coping strategies by individuals alone (Heijnders & Van Der Meij, 2006).

I do however question whether the women's fears were really about accidentally transmitting HIV or more about what others might think (or do) if it were known they were HIV+? Unfortunately these questions were not discussed but are areas which would benefit from further research.

7.4.3   Conclusion

The extent to which stigma is internalised is a fascinating phenomenon which appears to go beyond logic and is something so complex it is almost beyond comprehension and the realms of explanation. While there is much literature on HIV and stigma (Abel, 2007: Aggleton et al., 1998: Deacon, 2006: Fang et al., 2006: Gibson& Rohleder, 2006:

Goffman, 1959: Heijnders & Van Der Meij, 2006: Hutchinson & Ingram, 1999: Link & Phelan, 2001: Nyblade, 2006)), none of this literature truly encapsulates the depths and affects of stigma and how it is internalised by those affected.

Stigma, and the internalisation of stigma, is one of those phenomenons which may never be fully comprehended. While they appear to be two separate things, they are in reality intertwined and cannot be realistically separated. Even those who are directly affected struggle as was evident in this study.

There has been substantial research on the topic of HIV, stigma and internalised stigma, but what appears to be lacking is the translation (relaying) of these findings back to society. This needs to be done through multi faceted educational programmes aimed at all levels of society to encourage understanding, acceptance and in the reduction of HIV related stigma.

Positive Women Inc., attempted to address this issue in their 2007 'Destigmatisation Campaign', which was hugely successful however due to funding constraints no follow on from the campaign has so far been possible (J. M. Bruning, personal communication, October 1, 2008). This highlights the need for increased government and community funding and involvement to ensure awareness programmes for HIV in New Zealand are both consistent and sustainable for the prevention and destigmatisation of HIV on a national and international level.

When Kaufman defined *shame* as, 'an invisible wound, a sickness of the soul…a feeling of being seen in a painfully diminished way", he could just as easily have been talking about the internalisation of stigma. "We become ashamed in our own eyes", he said, "as we scrutinize ourselves and find ourselves flawed" (as sited in Evans, 1994, p. 8).

7.5   Self esteem and unacceptable behaviour

7.5.1   Inquiry reflections

A discussion was prompted around whether or not women living with HIV were inclined to accept behaviours, predominantly from partners, which were actually unacceptable because of their HIV status, especially those who where in relationships with a partner who did not have HIV.

Discussions on this topic echoed what was said in other themes during the inquiry but these were said in context to self esteem and unacceptable behaviour.

There were conflicting opinions around this. One woman said while she "wouldn't put up with unacceptable behaviour" (Participant, personal communication, September 10, 2008), she had however stayed in her last relationship, which was both physically and verbally abusive, for four years and her ex-partner had often tried to control her by using her HIV status. She wasn't sure why she had stayed with him for so long, even though prior to this relationship she had found generally men in New Zealand did not appear to be concerned that she had HIV.

Another woman talked about how she had recently left her marriage of only a few years. Her husband did not have HIV and she remarked;

> I feel he only married me because I had HIV and because of that he expected I would be humble and sad. He couldn't understand my desire to want to live like a normal person. In my country of origin, people relate HIV to death and I suspect my husband only married me because he thought I would soon die and then he could make claim to my possessions (Participant, personal communication, September 10, 2008).

While she put up with his behaviour for some time, eventually she ended the relationship as his treatment of both her and her son became increasingly (emotionally) abusive as he tried to control and manipulate her and constantly harassed her with threats of revealing her HIV status to others.

Another woman shared how she had been in her previous relationship for six years and for the last three years of the relationship she had put up with behaviour which was quite unacceptable before she finally left. She felt she had not left sooner for a mixture of reasons. She explained how when they first met she had been HIV+ but had not known it and only found out after they had been together for two years. By this time her partner had also contracted HIV and she felt some guilt around this, even though she had not known her own status at the time. She also felt as they were both living with HIV things might be easier and on top of that she was fearful no one else would want to be with a woman who had HIV, especially not a man who did not have HIV.

For another woman the situation was completely different, she had been married for nearly 15 years, to a man who does not have HIV. She said; "My husband is kind and has always been very good to me. We have a very strong, secure and happy marriage" (Participant, personal communication, September 10, 2008). As this woman met her husband not long after being diagnosed she said she had not had any experience of living with unacceptable behaviour.

What did come out of the discussion was that being a woman living with HIV required a lot of self confidence as the general feeling was it was easy to be taken advantage of in relationships. However everyone agreed 'self confidence' was an elusive thing. As one woman said, "You can't wake up and say, I am confident today" (Participant, personal communication, September 10, 2008).

All the women appeared to live with some degree of low self esteem as a direct result of their HIV status. Even the two women in the group who were openly out about their HIV status still grappled with issues around their HIV.

One woman wasn't sure "I wonder about HIV and how it affects me, and how do I stand up?" she said, it was something she hadn't really thought about before (Participant, personal communication, September 10, 2008).

Another woman commented how she had actually had low self esteem before she contracted HIV. "Having HIV has probably only reinforced the negative self worth I already had" she said and it was definitely a factor in stopping her from getting into a new relationship.

> I can't ever see being in a relationship ever again. I didn't feel confident with men before, so now I have HIV, they (a man) definitely won't want to be with me (Participant, personal communication, September 10, 2008).

7.5.2   Reflective analysis

It was evident all of the women in the group where affected by low self esteem to some degree and it appeared in most cases this was as a direct result of living with HIV.

Schutz (1998), suggests people generally want to feel good about themselves and this is linked to presenting a positive and favorable public image. Low self esteem on the other hand is associated with experiencing failure or criticism, both of one's own expectations and those of others. It is not surprising then that an HIV diagnoses, a disease shrouded with so much social and internalised stigma, would challenge a person's self esteem leaving them feeling insecure, threatened and stressed (Schutz, 1998).

Elifson et al. (2004), identified people with low self esteem may be more susceptible to contracting HIV as there is an association between low self esteem and sexual compulsivity and those at the lowest levels of self esteem have been found to engage in behaviours of higher risk as they lack the confidence to set boundaries in relationships and negotiating condom use. A strong link was also identified between excessive

physical, sexual, and emotional abuse in women during their formative years resulting in considerably lower levels of self-esteem (Elifson, Klein, & Sterk, 2004).

It is difficult to determine if what Elifson et al., (2004) identified in their study, was applicable for the women in this study as discussion on this topic did not go into that much depth. It does appear it may have been the case for one woman who identified she had low self esteem prior to contracting HIV. This woman was the same woman who in chapter 8.2.1. commented how she had probably slept around in an attempt to find love, implicating the existence of low self esteem and as a result she may have inadvertently put herself at risk of contracting HIV by engaging in 'risky or counterproductive behaviours'. Another consequence of this was her feelings of self blame around contracting HIV and thus compounding feelings of stigma and perceived discrimination.

While the women in this study verbalised feelings of low self esteem and examples were evident through the women's stories, there was also a clear contradiction as each of the women appeared to be remarkably strong and resilient.

Schutz (1998), alleged women with lower self esteem did not proactively participate in effectual problem solving/coping strategies and as a result regarded the outcome of situations less positively and tended to wait passively for change, often in self defeating ways. Conversely women with higher self esteem were much more positive and solution orientated who benefitted from sharing difficult experiences which helped to improve their self understanding and personal growth and also resulted in a quicker return to base line self esteem so might also possibly be less affected by stigma.

Even though the women in this study acknowledged they were affected by stigma and to some degree of low self esteem, yet all the women appeared to be positive, proactive and solution focused, each using coping strategies which were perceived to produce the maximum benefit for themselves and their families. So while low self esteem was evident, something else was also at play.

There is increasing evidence people living with either a life threatening or stigmatising condition can gain positive benefits from their experiences. In a study on stress-related growth on women living with HIV or AIDS by Siegel and Schrimshaw in 2000, 83% of women said they had at least one positive change in their lives as a direct consequence of their illness (Pretter, Schrimshaw, & Siegel, 2005). Some of these included things such as health related behavioural changes, positive self, spiritual and or religious development and even changes in the meaning and value of life. Some even said being

HIV positive had made them stronger, wiser and more understanding and made them want to live life to the fullest.

According to Parks (1998), highly stressful events are more likely to change existing global meaning systems, and therefore afford a greater potential for growth, which may explain the duality, that of low self esteem yet at the same time incredible resilience and strength, which was present amongst the women in this study, highlighting the impact of living with a stigmatising disease such as HIV.

Abraido-Lanza et al. (1998), found, greater self-esteem predicated growth after 3 years amongst the chronically ill yet it would appear even those with some degree of low self esteem may also gain self esteem as a result of coping with a chronic illness and stress related growth (cited in Pretter et al., 2005, p. 404 & 405).

Pretter et al. (2005), also identified African American women reported significantly more growth than white women and it was felt this was largely due to the fact they may already have had previous opportunities for stress-related growth possibly in regards to racial discrimination or poverty. While the study done by Burns et al., (2007) was specifically on new African migrants to the US, it would seem the same principle might also apply to new African migrants and refugees in New Zealand as they too would most likely have experienced previous opportunities for stress-related growth such as fleeing from politically unstable countries, living in refugee camps, poverty and as a result of migrating to a new country and possibly experiencing racial discrimination. This could be a significant consideration in developing strategies for supporting HIV positive African women migrants and refugees in New Zealand (Pretter et al., 2005).

A woman's self esteem is highly dependent on the intimacy established between herself and significant others in her life, on receiving emotional support and on the familial role, such as wife/partner and/or mother in which she functions. Women who feel the disease impacts on their social relationships and closeness to others, therefore may experience a more significant decrease in their self esteem and may be especially at risk for psychological impairment (Schutz, 1998).

Schutz (1998), suggests self esteem and coping are interrelated, and it is not clear whether self esteem determines different types of coping strategies or whether a third variable affects both self esteem and coping style. One might question if people with low self esteem may actually receive less support from their partners and so have poorer relationships or if they may be more difficult partners, harder to understand and get along with and as a result may need more support than partners with high self esteem. So one

might question, do people with low self esteem select partners who treat them less kindly, or do they engage in behaviours themselves which is likely to reduce the quality of the relationship?

Stress related growth and improved self esteem can be an important factor to consider in the design of interventions as a primary internal resource which may serve to enhance resilience in the face of stress, and to promote growth in the mastery and control over and adaption to a person's illness and coping with stigma. Cognitive coping strategies such as positive reappraisal have also been linked to stress-related growth as they often characterise efforts to find positive meaning in times of difficulty however no firm arrangement has yet been reached as to the most significant predictor for growth.

7.5.3   Conclusion

According to the women in this inquiry, low self esteem did appear to play a significant part at some stage in their lives as a direct result of living with a stigmatising disease such as HIV.

While the positive aspects of living with HIV were not discussed in great depth and while the women professed to be affected by low self esteem, there was however definitely a sense of enormous courage and resilience from the women and overall, each of the women outwardly, and in all other areas of their lives came across extremely self confident which I believe was further enhanced through the actions the women undertook during the course of the co-operative inquiry.

Interestingly all the women were either in a relationship with a partner or had children, highlighting what Schutz (1998), suggested, that a woman's self esteem is highly dependent on the intimacy established between herself and significant others in her life such as partners and/or children.

Self esteem seemed to be higher amongst the women who had a secure and stable partner and while some of the women had experienced unacceptable behaviours from (ex) partners in the past, none of them had stayed in those relationships, indicating some degree of (higher) self esteem. However all the women were still affected by stigma to some degree highlighting how stigma attacks a person at many levels.

7.6   Summary

All the themes identified during the inquiry sessions linked and intertwined in one way or another. The women acknowledged the biggest barrier to disclosure was directly related

to the (perceived) public perception and stigma associated to HIV and AIDS which generally related straight back to the fear of being judged or rejected and feelings of shame. Another strong factor was connected to protecting loved ones (as well as one's self) from discrimination. This included protecting children, partners and family and friends which is a very common phenomenon for women living with HIV who often put caring for themselves secondary to caring for and protecting family and friends in an attempt to create an atmosphere of normalcy (Abell et al., 2006).

A degree of low self-esteem and shame were commonly felt by all of the participants and would appear to be at the core of the internalisation of stigma as well as the internalisatoin of public perceptions, myths and understanding of HIV and AIDS.

Overall the themes identified were common and key concerns for the women who took part in the project and on a global perspective, results reported in this study were widely confirmed by other researches.

The women managed to accomplish a considerable amount in a relatively short time frame and they all expressed how they had gained a significant sense of achievement and personal satisfaction from being part of the process. Co-operative Inquiry is also about personal transformation and each and every one of the women who took part commented how they had benefited in some way from participating in the project. This is confirmed in chapter 7 from data recorded during the last inquiry session and in chapter 9 from feedback gained from a follow-up email/questionnaire sent to participants seven months after the completion of the project.

Some key areas of interest and possible areas for further research would be the interrelationship between irrational fears and stigma. Are they the same? Does one manifest the other? Where do these come from and how come they were so profoundly felt by the women?

Overall the aims of the inquiry were met and I believe co-operative inquiry as a methodology, especially in the context of this inquiry, was useful and productive. If I were to do it over again however I would recommend having only one very specific aim for the group to focus on when working with a short time frame.

8 Seven month follow up

8.1 Introduction

A follow up was done seven months after the completion of the project in the form of an email questionnaire. The purpose of this follow up was to see if participation in the co-operative inquiry had made any lasting impact on the women.

8.2 Participant Feedback

Five questions were asked of the women and the responses were significant.

1. What impact (if any) did taking part in the co-operative inquiry have on you?

> It was incredibly encouraging and empowering for me. I found listening and sharing on HIV related issues (which I never discuss) very helpful to me emotionally. After our 5 weeks together I felt more empowered and able to be who I am and went on to enroll in a 2 year course (Participant 3, personal communication, June 4, 2009).

> It made me reflect on my HIV status more intensely than I had done for a while and bought issues to the forefront of my mind that I had hidden. It was also interesting to hear how other people thought about their HIV and how it impacted on each of our lives but in very different ways (Participant 4, personal communication, June 5, 2009).

> Mostly it highlighted to me how most of us feel very similar. I used to think I was the only one who felt like I did, and that I was being silly etc. but I see that the way I feel is very common. It has made me even more determined to work around the destigmatisation of HIV as I feel it is so profound, so complex, so hurtful and isolating and mostly…so unnecessary (Participant 5, personal communication, June 5, 2009

> Very encouraging and building, knowing that there are other women like me out there with the same issues (Participant 2, personal communication, June 7, 2009).

2. What was the most significant outcome (if any) for you from taking part in the co-operative inquiry?

> Realising that I wasn't alone in some of my thinking on how I felt and perceived myself. I no longer say "I am" hiv +ve I am so much more. I am a lot more aware of how I use words to describe myself (Participant 3, personal communication, June 4, 2009.

> I think it made me focus more on myself and to ensure that I actually did some work around the feelings that came up (Participant 4, personal communication, June 5, 2009).

The most significant outcome for me was that it re-confirmed my determination to work around educating communities about HIV in particular for the purpose of destigmatising HIV and AIDS, and also to work with PLWH communities to overcome their fears and internalisation of stigma and to not feel ashamed (Participant 5, personal communication, June 5, 2009).

Remaining strong and focused. Nothing should change after being diagnosed, if anything aiming higher than before (Participant 2, personal communication, June 7, 2009).

3. Has anything changed for you since taking part in the co-operative inquiry. i.e. have you disclosed to anyone, feel more confident, less fearful etc?

Yes I do feel more confident and I have told a few people. I actually feel less ashamed and less afraid of people knowing. I feel as if I don't have to hide and protect myself so much (Participant 3, personal communication, June 4, 2009).

I'm not sure whether it was the inquiry in itself or a combination of things that were happening in my life at the time but since our meetings I have disclosed to some more people and also I am feeling a lot more sure of my sense of self. As in I am the person you know but now you just know a bit more about me! I don't say I am still the same person I was before HIV because I am not. Having HIV has changed who I am, but I also feel that I am still a worthy individual. (although sometimes that takes a bit of convincing! To myself)

The shame does seem to be a bit less these days and I think that is a direct result of the work done in the collaborative inquiry. Realising that if I feel ashamed and hide then how can I expect others i.e. Joe Public to have any other reaction.

I have also started more personal therapy sessions since then (Participant 4, personal communication, June 5, 2009).

Nothing has changed as such except that I am more determined than ever to continue working on issues around stigma on both a personal and community level (Participant 5, personal communication, June 5, 2009).

I am more confident, and it's some (thing) I talk about freely to those I have disclosed to (Participant 2, personal communication, June 7, 2009).

4. What recommendations do you have about what can be done in regards to alleviating or helping to reduce stigma, both on an individual and a societal level and for those living with HIV?

> Education of the whole population. It is great to have regular articles in mag. Etc that show the face of HIV, ordinary men and women. There are still a lot of myths and half truths and fear within the community that education can help to alleviate.
>
> Hiv+ve people can also help alleviate some of the stigma by telling people in their lives. Once people start knowing people on a personal level that live with HIV it becomes less of a big fearful thing.
>
> +ve people meeting and being able to talk and discuss issues helps to reduce the sense of isolation and can empower and encourage one another (Participant 3, personal communication, June 4, 2009).
>
> I debate with myself about whether the stigma I feel comes from society or from within myself so I do think that ways of increasing the self-esteem of individuals with HIV infection (myself included) does help reduce the sense of shame and low worth that surrounds me. The more society sees people with HIV in the community and can relate to them as like themselves or their neighbours/friends or children, the greater the chances we have of reducing stigma. So I feel positive people speaking out will make a difference. The more people I can personally tell also will affect the way they see HIV and the way I see myself (Participant 4, personal communication, June 5, 2009).
>
> I think HIV awareness and education, especially in schools, is severely and detrimentally lacking in New Zealand. Not only do we need to educate the youth, but we need to educate the educators. HIV awareness and education needs to start early so that it is 'normalised'. This will not only help reduce transmission rates but will also reduce the stigmatisation of HIV and AIDS.
>
> There needs to be more interventions/programmes available for those affected by HIV to help raise self esteem and reduce internal stigma. PLWH should be more involved at both a governmental and community level on issues relating to HIV and AIDS awareness, prevention and destigmatisation (Participant 5, personal communication, June 5, 2009).
>
> Sensitising the N.Z. public more about the illness. More education should be done especially to health workers so that they look at HIV like diabetes is and not unclean or death (Participant 2, personal communication, June 7, 2009).

5. Is there anything else you would like to add?

> Thanks Jane I found the whole process enriching. It was great to meet up with others and be inspired by each ones strength and courage. It was a real privilege and definitely has been empowering for me (Participant 3, personal communication, June 4, 2009).

> Thank you Jane for tackling this subject in your research and I hope that it too will have repercussions outside the direct academic audience it is initially going to be seen by. I think that it will have an important effect on those who read it (Participant 4, personal communication, June 5, 2009).

> Being part of the inquiry was a very empowering experience for me however it also left me feeling very frustrated. The government talks about 'primary health care' yet HIV education, particularly amongst the general populous is largely ignored, but it was evident during the inquiry that this is severely lacking. Rather than taking the 'ambulance at the top of the cliff' approach (primary/preventative care), it seems the ambulance is no-where in sight as New Zealand remains slow to learn lessons from the rest of the world. Government funding around HIV is reserved for education and prevention programmes of 'targeted populations', which only feed into the stigmatisation and marginalisation of these sectors of the community, while not really making much difference, and those living with HIV are treated as relatively insignificant (Participant 5, personal communication, June 5, 2009).

> There should be more get-togethers done in the future as it gives people chance to air out their feelings, fears and any other things going on in their journeys. Thx (Participant 2, personal communication, June 7, 2009).

8.2.1   Reflection

While co-operative inquiry is a wide ranging science about any aspect of the human condition, one of the main goals of this inquiry was of personal transformation for the participants. It was evident by the feedback from the seven month follow up that participating in this inquiry had a significant impact and personal transformation occurred for all of the women who took part. These transformations were not initially evident immediately after the inquiry sessions, however we can see, seven months after the inquiry, for some women the impact was life changing as they undertook new life courses and paradigm shifts in different areas of their lives such as their language, self image and mind sets as women living with HIV, thus helping to reduce the internalisation of stigma.

The impact of the co-operative inquiry process during this project indicates co-operative inquiry could be a constructive and beneficial programme of intervention for those living with HIV as a way of responding to HIV related stigma and to empowering the populations most affected. It also highlights and supports the need of the involvement of people living with HIV as active participants to encourage positive perceptions amongst people living with HIV and emphasizes the importance of support networks and their contribution to assisting people living with HIV and towards the greater societal change around HIV stigma and discrimination.

An interesting observation in the seven month follow up was that the feedback given by the participants, was very much in line with what was identified in the 'reflective analysis' done (by the researcher), highlighting the significance of research being done by and with those directly affected as through the process of co-operative inquiry, the participants (and researcher) were able to engage from a real sense of shared experience, and understanding. I question if the same level of understanding would have been achieved if this research has been done in a different format and by a researcher who was not HIV+.

8.3   Update on Actions

Since the completion of the co-operative inquiry sessions in October 2008, the outstanding actions from the co-operative inquiry were handed over to Positive Women Inc. Progress on these actions are as follows.

- A copy of a booklet produced by the International Academy of Education (IAE) for the International Bureau of Education, called 'Preventing HIV and AIDS in schools' by Schenker & Nyirenda (2020), has been adapted by three third year nursing students from Auckland University who did a three week project for Positive Women Inc. as part of their community studies. This booklet has been adapted to fit a New Zealand context and incorporates education around the destigmatisation and prevention of HIV transmission. The booklet is currently in its first draft. The next stage will be for the Board of Positive Women Inc. to edit and to seek funding for publication. Once booklets have been printed they will be distributed to teachers training colleges and secondary schools who are interested in them.

- Positive Women Inc. is to run an "HIV Youth Road Show" which will travel the country in the summer of 2010. The aim of the Road Show is to raise awareness of HIV by using youth ambassadors as educators in an effort to reduce HIV stigma while at the same time providing an HIV prevention message. It is hoped that

organisations such as YWCA (who have already expressed and interest) and other youth focused organisations will work together with Positive Women Inc. in this project.

- Unfortunately the Positive Women Inc. Youth Forum scheduled for November 2008 did not work out as planned and so did not discuss the NZAF HIV booklet. While there are no plans currently in place to do anything about this in the short term, Positive Women Inc. is keen to pursue this in the future by getting feedback from youth on the current booklet and to work, in conjunction with youth and possibly other associated organisations, to produce a more 'youth friendly booklet'.

- Other actions proposed as a result of the co-operative inquiry, while not yet auctioned, are on the 'to do list' and will be addressed as soon as time and resources are able.

8.3.1 Reflection

Even thought the time frame for this co-operative inquiry was relatively short and the aims of this project, substantial, it is evident significant actions were undertaken by the participants and these continued to be followed through by Positive Women Inc.

As well as the personal transformation experienced by the women who took part in the inquiry process, there is also a huge sense of pride by the women of the actions which they initiated. While some of the actions were not able to be fully completed during the course of the inquiry this did not appear to diminish the sense of accomplishment felt by the women.

8.4 Summary

Regardless that some adaptions had to be made to ensure the methodology of co-operative inquiry would also comply with the academic requirements of a thesis for a masters degree, overall the aims of the project were met, and even succeeded expectations both of the women and from myself in my capacity as the researcher.

The process of the inquiry was intimate and personal, yet constructive and beneficial. A participatory and inclusive environment was achieved, even with the inclusion of an independent (outside) support person and scribe. The inclusions of these two people did not interfere with the process or the outcomes but instead I believed only enhanced the process as their presence enabled me to be fully emerged in the inquiry process but with both practical (data collection) and emotional support.

9 Conclusion

This project explored the impact of stigma on five women in New Zealand living with HIV using the innovative methodology of co-operative inquiry. An inductive methodology, co-operative inquiry is not based on validating unconfirmed hypotheses and is generally not reliant on the underpinnings of any theory. However to comply with the academic requirements of this theses, feminist grounded theory, which is also an inductive approach to research, was incorporated into the study.

While no theory was in fact generated as a result of this research, this was something which had been anticipated due to the time constraints of the project. However generating theory is not the sole outcome required when engaging in grounded theory.

An inductive coding process to analyse the data generated during the inquiry sessions was used. From this initial analysis what emerged was a grouping of themes, which, had there been more time, would have been the basis for determining the next direction of research and towards the analysis of secondary data (Brine, 1994). As it was, the findings from this first phase, the themes and the actions undertaken, were used as the bases of analyses for this thesis.

The most significant outcome of this project was the transformation that nearly all of the women underwent during the process of the inquiry. Through the sharing of experiences and connecting with other women also affected by living with the stigma of an HIV diagnoses, these women all reached a level of consciousness which they previously had not been connected to. This can be seen in the feedback provided in the follow up seven months after the research project which highlighted significant changes in the lives of all those who responded and is a key aim of co-operative inquiry (Heron, 1996).

I believe the second most significant outcome from this project was the level of consciousness which the women experienced in regards to their own understanding of HIV and stigma. Consciousness-raising is an empowering component for both individual and community development as it enables a move towards action for change. However the possibility to enact on a process of action (for change) must also be made available otherwise there is no point in people being able to identify their needs (Ife & Tesoriero, 2006).

Opportunities to initiate and participate in action (for change) was enabled for the women during this project as they collectively and co-operatively moved through the stages and cycles of the inquiry. Due to the limited time frame, not all of these actions were seen

through to a conclusion however the outstanding actions were passed on to Positive Women Inc. The implementation of these actions are ongoing and are expected to result in further significant outcomes in the future.

The key themes identified in this study were consistent with findings in other research on the subject of women, HIV and stigma however two areas which I felt were very significant were; 1) The depth of irrational fear experienced by the women around the possible accidental transmission of HIV through casual contact with others. 2) The inability of the women to be able to disassociate themselves from the virus i.e. I am HIV+ so I *am* the virus (rather than I *have* a virus).

It might be argued that these are in fact influences of both external and internalised stigma but I suspect there is something more going on. Had this project continued these would have been the two areas I believe the project would have focused on and through the process of both co-operative inquiry and feminist grounded theory, I believe some theory would have been generated.

The underlying drive which motivated most of the actions undertaken during this inquiry was the concern over the lack of awareness and education of HIV for secondary school teachers and students in New Zealand. This concern was generated both from a concern that teachers lacked the correct information to pass on to their students and secondly that the students did not receive enough (accurate) information to help raise their awareness of HIV for both preventative and destigmatisation purposes. The women felt strongly that attitudinal shifts around HIV and stigma needed to be instilled early and that this should start at school, but also important was that the teachers needed to have training to enable them to teach the topic correctly.

From the literature review done for this thesis and through discussions undertaken during the inquiry process it is clearly apparent that stigma is both a societal and individual construction. If society and individuals are capable of constructing labels, metaphors, stereotypes and interpretations, then so too are they capable and responsible for the implementation of interventions and to promote new paradigms.

Recommendations which I believe, as a result of this research, which need to be incorporated in future strategies or interventions in the destigmatisation of HIV must include or at least consider the following:

Recommendations

- Interventions/programmes need to be available for people living with and/or affected by HIV to reduce internalised stigma and shame and to help improve self esteem.

- The process of co-operative inquiry be considered by HIV support networks as an intervention for those living with and affected by HIV as it enables participants to proactively work together through sharing experiences and exploring ways to overcome or manage life situations and through this reflective process, attain personal transformation.

- Co-operative inquiry would also be a useful process for others to engage in, those not directly affected by but involved in the HIV sector, to identify strategies around HIV awareness and education.

- Destigmatisation of HIV needs to be made a priority by both governmental and community organistions. Destigmatisation of HIV will help to improve the lives of those affected as well as being another tool to demystify HIV with the effect that society is better educated, more knowledgeable and thus reducing fear resulting in greater acceptance of those affected by HIV.

- HIV awareness and education needs to be incorporated as compulsory secondary school education as an independent module, or curriculum agenda. HIV is a global epidemic and it is important for New Zealanders to understand this for their own health as well as enabling understanding and acceptance towards those affected. This needs to start at secondary school level as part of early education.

- How to teach HIV awareness and education needs to be incorporated in teachers training college circular.

- HIV awareness and education resources need to be made available for both teachers training colleges and secondary schools.

- A greater focus on HIV awareness and education for healthcare workers so as to help destigmatise HIV and to ensure healthcare workers treat clients living with HIV with dignity and respect.

- Care needs to be taken to ensure HIV is not portrayed as 'evil' as a means of prevention education as this feeds into societal fears and further stigmatises HIV and AIDS and those living with the disease.

What is evident is that there needs to be less talk and more action. Research is useful and should continue to investigate data on both a qualitative and quantitative level, but

what is most urgent is for these studies to be implemented though constructive action by government, communities and individuals.

The involvement of people living with and affected by HIV and AIDS is both paramount and instrumental to all HIV related advocacy, policies and interventions. Unfortunately many people living with HIV are too afraid to be involved or to speak out as this would involve having to disclose their HIV status. While the disclosure of one's HIV status is a personal issue as is the disclosure of any personal medical condition, the major difference however is that people should not *need* to be afraid to disclose their HIV status for fear of social stigma and discrimination.

In conclusion: The Starfish poem provided an inspirational metaphor for the women who participated in this inquiry. There was consensus amongst the women that making a difference to as many people as possible through initiatives such as education and conscious raising made a valuable contribution to 'the war on the destigmatisation of HIV'. It is therefore fitting and appropriate that this poem concludes this project:

The Starfish Poem

Once upon a time there was a wise man who used to go to the ocean to do his writing. He had a habit of walking on the beach before he began his work.
One day he was walking along the shore.
As he looked down the beach, he saw a human figure moving like a dancer.
He smiled to himself to think of someone who would dance to the day.
So he began to walk faster to catch up.
As he got closer, he saw that it was a young man and the young man wasn't dancing, but instead he was reaching down to the shore, picking up something and very gently throwing it into the ocean.
As he got closer he called out, "Good morning! What are you doing?"
The young man paused, looked up and replied, "Throwing starfish in the ocean."
"I guess I should have asked, why are you throwing starfish in the ocean?"
"The sun is up and the tide is going out. And if I don't throw them in they'll die."
"But, young man, don't you realize that there are miles and miles of beach and starfish all along it. You can't possibly make a difference!"
The young man listened politely.
Then he bent down, picked up another starfish and threw it into the sea, past the breaking waves and said – "It made a difference for that one." (Unknown, Unknown)

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11 Appendices

Appendix A

Ethics Approval

Jane Bruning
46 Eskdale Road
Birkdale
Auckland

30 June 2008

Dear Jane

Your file number for this application: 2008.841
Title: Stigma in Women in New Zealand living with HIV or AIDS

Your application for ethics approval has been reviewed by the Unitec Research Ethics Committee (UREC) and was **approved** on 25 June 2008 for the following period:

Start date: 25 June 2008
Finish date: 25 June 2009

Please note that:
1. the above dates must be referred to on the information AND consent forms given to all participants
2. you must inform UREC, in advance, of any ethically-relevant deviation in the project. This may require additional approval.

You may now commence your research according to the protocols approved by UREC. We wish you every success with your project.

Yours sincerely

Deborah Rolland
Deputy Chair, UREC

RMOL ref#: 1160

cc: Ksenija Napan
    Helene Connor
    Cynthia Almeida

Information for participants

STIGMA AND WOMEN LIVING WITH HIV or AIDS

My name is Jane Bruning. I am a student in my final year of dong a Masters Degree in Social Practice at Unitec. I am also a woman who has been living with HIV for the past 20 years. Part of the Masters Degree programme involves that I undertake a research paper on a subject of my choice. The research topic I am keen to look at, as it is one that I have also been affected by, is around the impact of stigma on women in New Zealand living with HIV or AIDS. This will initially be discussed at the HIV Women's Retreat to be held in April 2008 and has been given approval by the Board of Positive Women Inc.

What we will do
The initial idea for this research is to look at the impact of stigma on women in New Zealand, living with HIV or AIDS and to possibly discuss strategies on how to overcome or manage these impacts. The methodology proposed for this will be done in the form of a 'Collaborative Inquiry', which means that as a group we will together (collaboratively), discuss, inquire and explore the topic of stigma as a result of our own experiences as women living with HIV or AIDS.

What it will mean for you
You will be invited to:
- share your experiences around stigma as a woman living with HIV
- discuss possible ways for us to overcome or manage these
- reflect on the process of the inquiry; and
- hopefully gain some learning from both the discussion and the process

This will be done via a series of group meetings, possibly 5 meetings, over a two month period each lasting for about 90-120 minutes. It is proposed to hold the first of these meetings in July 2008 at the Offices of Positive Women Inc.

The sessions will be facilitated by Gabriela Mercado, a trained psychotherapists and an experienced group facilitator. My role will be both as a participant in the discussion group and to analyse all recorded data for the research project.

The idea of a collaborative inquiry is that we will *all* be involved in the leadership and direction of the discussion as equal participants. The role of the facilitator will be to ensure the process of the inquiry is followed. This process will be decided by all participants on the first meeting.

Discussions will be recorded by an independent recorder who will record everything through diagrams on large sheets of paper. This person will be at the back of the room and will not take part in the discussion. Towards the end of each session everyone will be invited to go over what has been recorded to ensure that interpretations are accurate. All features that might identify you or anyone in the group will be removed. Your anonymity will be secure at all times.

Both the facilitator, the recorder and all participants in the inquiry will be required to sign confidentiality forms so you can be assured that your identity remains totally confidential.

To fully embrace the concept of a 'collaborative inquiry' it is recommended we continue our discussions over a period of time, possibly about 5 meetings over a period of 5/6weeks but we can discuss this process at the first meeting. You may decide that you would like to attend the initial discussion but not continue with the follow-up sessions. We may also decide that keeping a written journal might be a good way of keeping the inquiry going and help us to reflect our thoughts and feelings. Other options might be that we chose to document our findings in the form of a book or in a paper to present to the Ministry of Health or for other academic journals in the hope that they may help in the provisions of services and understanding in regards to women and HIV and stigma. These are all options we can discuss, as well as any other ideas you might have.

The services of three psychotherapists will be available should any issues arise which you feel you would like to discuss in more detail and on a one to one basis. All three therapist work for the New Zealand AIDS Foundation and have an understanding of issues to do with HIV.

If you agree to participate, you will be asked to sign a consent form. This does not stop you from changing your mind if you wish to withdraw from the project. Because of the time schedule of this project, it would be appreciated if any withdrawals are done within 2 weeks after the initial discussion group has taken place.

I appreciate that there is a considerable amount of time and effort required of you for this project but I believe the outcome will be beneficial for all those who take part. I also believe we will be able to gain some very valuable information to share and to use when fighting for rights and services for women and families living with HIV in New Zealand.

Your name and any information that may identify you will be kept completely confidential. All information collected from you will be stored on a password protected file and only you, the two research supervisors and I will have access to this information.

Any costs that you may incur as a result of participating in this project will be reimbursed to you, including the cost of petrol.

Please contact me as soon as possible to let me know if you would be interested in being part of this ground breaking project or if you need more information. You can also contact the research supervisors at any time if you have any concerns about the research project:

I look forward to hearing from you. Thank you so very much.

Researcher:
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UREC REGISTRATION NUMBER: 2008.841

This study has been approved by the UNITEC Research Ethics Committee from 25 June 2008 to 25 June 2009. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 7248). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Session Plan

First Meeting - 3 September 2008

---

1.   **Welcome and introduction**

      Each person to introduce themselves and their role

      a.   Jane – researcher and co participant

      b.   Gabriela – support person

      c.   Simon – Recorder

2.   **Group Introduction**

      a.   Name and

      b.   Why you are interested in this project?

3.   **First meeting to set up framework of session**

      a.   Confidentiality …what does it mean?

      b.   Explain about informed consent

      c.   Respecting each other's point of views

      d.   Non judgmental

      e.   One person to speak at a time

      f.   Speak from the 'I' perspective – about sharing experiences

   Encourage Feedback and participation throughout this process from the group so that frame work a cooperative process

4.   **Explain purpose of research**

      a.   Share experiences around stigma as women living with HIV

      b.   Explore ways to over-come or manage the impact of stigma

      c.   Reflect on the process of the inquiry

      d.   Personal gain from both the process and actions taken

      e.   To enable Jane to research for masters degree

5. **Explain methodology: Cooperative Inquiry**

   Cooperative = together

   Inquiry = discussing, questioning, discovering (actions)

   The process of cooperative inquiry does not lead itself to a structured agenda. There are no hypothesis and no structured research questions. The process will be open, the direction and aims will be guided by you, the participants. The only constant will be that we focus on women living with HIV and stigma.

   Proposed group discussion over five sessions with individual/group actions phases in between scheduled session or during each session…depending on what the group decides.

   The group leads the direction of the inquiry. Everyone involved as co-participants

   Explain, this is actually a 'modified cooperative inquiry' due to the involvement of Gabriela and Simon. While both have roles to assist in the process i.e. recording and support, they will not be participants in the inquiry.

   Address any questions or concerns

6. **Explain phases of Cooperative Inquiry**

   a. **First Session**
      i. First part of session spent on setting up the framework for this and next 4 sessions
      ii. Second part of session to start discussion around 'What does stigma mean for us"?
      iii. Towards the end of the session Simon will summarise what was discussed by going over the mind maps.
      iv. Decide on an action to undertake over the next week

   b. **Second Session:**
      i. Check in round
      ii. Feed-back on actions taken over the week and
      iii. Feed-back on impact of actions/process of inquiry
      iv. Discuss other possible actions
      v. Summarise session through mind-maps
      vi. Decide on an action

     c.   Third and Forth Sessions: to repeat cycles of discussion, reflection and action

     d.   Fifth Session:
         i.   Discuss and reflect on process of inquiry and project

Provide opportunity for questions

7.   Inform psychotherapists will be available and provide details. Free service

8.   Invite participants to join

9.   Informed consent:
     a.   Read over together…answering any questions and concerns
     b.   Each participant to sign information and written consent forms

10.   Participant Demographic information forms.
     a.   To be filled out and brought back at next session.

11.   Tea/Coffee Break

12.   Start first phase of inquiry:
"What does stigma mean to/for us"?

13.   Summarise Mind Maps

14.   Decide on Actions

15.   Check in, confirm date and time for next session and close

End

Appendix D

Unitec
NEW ZEALAND
Te Whare Wānanga o Wairaka

Participant consent form

STIGMA AND WOMEN LIVING WITH HIV or AIDS

I have had the research project explained to me and I have read and understand the information sheet given to me.

I understand that I don't have to be part of this if I don't want to and I may withdraw at any time prior to the completion of the research project.

I understand that everything I say is confidential and none of the information I give will identify me and that the only persons who will know what I have said will be the researcher and her supervisors. I also understand that all the information that I give will be stored securely on a computer at Unitec for a period of 5 years.

I understand that my discussion with the researcher will be taped and I understand that I can see a copy of the finished research document.

I have had time to consider everything and I give my consent to be a part of this project.

Participant Signature: …………………………..…….. Date: ……………………

Project Researcher: …………………………..……….. Date: ……………………………

UREC REGISTRATION NUMBER: 2008.841
This study has been approved by the UNITEC Research Ethics Committee from 25 June 2008 to 25 June 2009. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 7248). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Unitec
NEW ZEALAND
Te Whare Wānanga o Wairaka

PRO-FORMA CONSENT FORM - ADULTS

TO: _____

FROM: _____

DATE: _____

RE: STIGMA AND WOMEN LIVING WITH HIV or AIDS

I have been given and have understood an explanation of this research project for the *Masters in Social Practice Degree.* I have had an opportunity to ask questions and have had them answered. I understand that neither my name nor the name of my organisation will be used in any public reports, and that I may withdraw myself or any information I have provided for this project without penalty of any sort.

I agree to take part in this project.

Signed: _____

Name: _____

Date: _____

UREC REGISTRATION NUMBER: 2008.841

This study has been approved by the UNITEC Research Ethics Committee from 25 June 2008 to 25 June 2009. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 7248). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

HIV and Stigma - A Collaborative Inquiry

Demographic information on group participants

These questions are being asked as they may help to identify trends when analysing the information which comes from the process of this collaborative inquiry. All information is highly confidential; you are not required to identify your name and any information provided will only be used for the purpose of this project.

---

1. How old are you? _____

2. What is the ethnicity you most identify with?

    ☐ New Zealand Pakeha/Kiwi

    ☐ Maori

    ☐ European: Which country? _____

    ☐ Pacific Islander: Which island? _____

    ☐ African: Which country? _____

    ☐ Other: _____

3. How long have you lived in New Zealand? _____

4. How long have you been HIV+ (that you know of)_____

5. Are you on HIV Medications?   ☐ Yes (go to question 6)

                                      ☐ No (go to question 7)

6. How long have you been on HIV Medications? _____

7. What was your last CD4 count?_____

8. What was your last Viral load count?_____

9. Are you married/in steady relationship   ☐ Yes (go to question 10)

                                            ☐ No (go to question 11)

10. How long have you been married/in relationship? _____

11. Do you have any children? ☐ Yes (go to question 12)

☐ No (go to question 14)

12. How many children do you have? _____

13. How old is your child/children?_____

14. Who have you told about your HIV status?

☐ My mother

☐ My father

My brothers and sisters

☐ All
☐ Some

My children

☐ All
☐ Some

☐ My close friends

☐ My GP

☐ My Dentist

☐ No-one

☐ Other: _____

Thank you

gain some empowerment from process

stigma

boundaries of research

reflect on process

Explores what we feel by stigma

ways of overcoming stigma

identify themes from mind map

no set structure

first session

Summative mind map at end

we need to do something

eg write a book, discuss a chapter each week

eg positive affirmations

action based research method

Methodology is what we decide

some action

can be what we want it to be

an anti anti-stigma campaign

not repetition

at end of session all will inspect and check validity

Mind mapping as means of data reduction

enables themes to emerge which may be investigated further

cooperative enquiry

flexible

boundaries set by group

enables thoughts and connections to be seen immediately

you can decide

keep a journal

Method of recording

not a therapy for a masters degree thesis for Jane

3-4 people is ok

will discuss whether others can join in

masters idea started from this conversation

eg shame of HIV even after living with it for 12 years

Stigma

not a lot of research on NZ context on women

lots of research for men

cooperative enquiry

what is happened/thought about during week

Introduction

purpose of project

methodology

Profile of group

Process

FANTASTIC FOUR today

how stigma affects lives

Ideally needed 5-8 people some unable to attend

taped but not transcribed

age no names included

how long HIV

becomes part of research

decided to how it?

all can have a go at facilitate

no names used

five weeks duration

cooperative enquiry

researcher steps back

all involved in group

can change facilitator for group

time is ok 10-12 noon Wed

get framework set out first

people

Stigma and women living with HIV

blank form will go into thesis

only person who is superior

will have name on

fill out consent form to say understand and be in project

Simon is a mind mapper

Gabriela role make tea and emotional support

psychotherapist works at Burnett Centre

this is your support mechanism for the process

provides free counselling

names will not be used

Intro

experiences of stigma

thanks to FANTASTIC FOUR for being here

Initially Gabriela was going to facilitate

won't say hello first up to group

OK about being acknowledged

all data kept locked away

confidentiality

housekeeping

due to age

want to help out

way I think of HIV (normal in my life)

want to support Jane and have admiration for her

for group

will be written so group cannot be identified

any time you can leave, pull out

Interested to see what comes out

When first saw project thought

removed self so don't get stigma

made sure kept self safe

thinking what does stigma mean to my children

happy to tell story but not be identified

happy for experiences to be out

small place everyone knows everyone

concerned about points of contact that can be identified

no right or wrong

our thoughts, feelings

own what you say 'I' word

should respect all in group

no judgements

Stigma and women living with HIV

ACTIONS

- well start with your thoughts
- Next time
- 1. what will they add?
- how often will they come?
- will they commit
- inclusion of other people in group that couldn't make today
- happy to leave to J to ensure OK
- Journal
- dynamic?
- think about what talked about
- 1. what if things to do
- think about some that come up
- a message
- They asked sensitive questions
- Story of being a school nurse and 13-17 year old boys had attitude to send 'bad' people away
- reflects what some people think
- talked to 14 year olds at Papakura
- showed them life on powerpoint
- Most NZers are open minded
- HIV too dangerous should be (re allowed to work)
- might be an age thing
- But always have bigots
- Story of HIV people should be put on an island on news
- need to get into schools
- not allowed to talk about sex to under 14/15 year olds
- got to start when young
- parents don't want their kids to have this information

- e.g. Short land Street
- programme run TV shows sex
- Yet ads and pop music are full of sex — split / distance
- Sex is a 'no-no' we don't go there
- society has a 'hiccup' with sex
- If it was the first thing they knew maybe they wouldn't have been friends with him
- They had already made their judgement
- His friends were fine when he told them
- I was protecting him and he was protecting him
- people think what kind of life did I lead
- people think I must have been a prostitute
- gay thing / sexually transmitted
- drugs
- didn't want people to judge me and say got what you deserved
- huge sense of shame
- but if energy
- in the early days felt shame
- in sense of society wrong to have lots of sex
- Shame
- promiscuous / slapper
- not my fault
- education of people can only happen through us
- either won't listen or not educated
- big battle as people are cynical
- we only listen to personal stories didn't need to
- did campaign 10 years had email saying ch my life
- experience is spent lot of years keeping a secret
- angers me that 'society' created stigma that everyone believes
- leads to discrimination
- spent years of being afraid of people knowing
- We only have stigma because people not educated
- problem is the reality of things
- don't test it out so don't know reality of stigma
- had to tell health professional that HIV
- not an issue
- health professional did not react
- built it up to be a big thing, fear
- because doc a box can longer to d
- he was very supportive
- told son had HIV and not to tell anyone
- He kept a secret untold came out about HIV
- Sharing thoughts on what stigma means
- rejection or Being rejected
- teen out for 4 years but have experienced no rejection in this time
- comes from somewhere
- fear of judgement being put in a box
- Hurting because me when they don't
- hate being put in a box
- I thought my responsibility to tell
- fear of being rejected by others when tell them
- thought of 25 years ago
- more so about men
- men of older generation think HIV = AIDS
- not fair as only have a virus
- fear not want to tell my friends
- not afraid to tell but afraid of rejection
- don't let people know me, protect myself
- news had experience of rejection but have been careful who tell
- told children but didn't tell them to tell others
- children wouldn't tell others as felt shame
- concern such ignorance about how get it so kids think will contract it from my children
- Your 'good mother' must have had sex

silent, not spoken about HIV → you walk alo

My partner can't get same support as didn't or couldn't tell others about me

worried about repercussions for him and me

cross about stigma

don't get support in the community

have to hold all this in

huge support that we don't get

get no support

for something else all this support exists but no one rallies round me

sister rang me for a week, then nothing

Did let them know I am not well

family think diabetes is worse than HIV

see me as strong and I have to deal with it myself

don't get support

discrimination happens

feel like a teenager again

feel so special and changed how I feel about myself

found one who loves me

to some guys status doesn't matter

I spoke to his partner and offered support

thought it was cancer

thought he had something else

wanted to know if it was HIV

can talk in a public place about cancer

diabetes friend

disassociated from me

family treat me different, don't get same help

feel shit about this, pisses me off

happens constantly in my family

scared of me won't look after me

lots of people helping him

got lots of support around him

not enough to keep us together though

When found out he was positive felt he wouldn't leave me

hope my partner is negative

how do I stand up?

wonder about HIV and how this affects me

have to worry about condoms

negative people don't

no man will want to be with me

always worried

can't wake up and say I am confident today

An elusive thing

internalised stigma

identifying with HIV

talk about being HIV not having HIV

welcome to fabulous five

language

chose because you are you to be with

e.g. difference talk about having cancer, not being cancer

society deals by pigeon hole and say gay disease

HIV fits into this category in beginning

about something can't explain and can be hurt by it

socially generated concept that is internalised

review process from last session

review mind map from previous session

check in feedback

form on wall to remind of process

outline discussion

Stigma and women living with HIV
10 Sept 08

behaviour

do we accept behaviour from others because of our status?

No, won't put up with bad behaviour

women and HIV prepared to accept certain behaviours

need self-confidence

otherwise anyone can take advantage

feedback

looked for definition of stigma

everyone still processing from last week

people been very busy and stressed

week from hell

aaarrgghhh

last week discussed process and was about warming up

In my country stigma is big

some people look so well who are HIV

being positive about their lives

husband married for advantages/gains of status

husband tried to manipulate and harass using HIV status

different way of stigma

people relate HIV to death

want people to know about it and treat HIV as normal

husband trying to control

ex partner also tried to control through HIV status

want to help others with story

ex partner wanted me to be humble and sad couldn't understand desire to live like a normal person

concerns about how his children will react now living together (new partner)

stress has big affect on body with HIV

Central node: Stigma and women living with HIV — 10 Sept 08 — (2)

no judgements on sex and promiscuity

understand about sex

not a dirty thing

after 20 years my family see me as sick not as having HIV

on my birthday and Xmas my family support me

think they tell from looking at others

who do we target first — teachers, PTA, children? — which group first?

what is a PTA? How much? how much influence do they have medication, take pill live longer healthier what's the problem

we don't have to write it as a group. Could do principals to sell into place

will ask my children's school

would like to talk to principal + see materials that use — ask family planning

one of my children came home and said "mum should be dead by now"

sense is that it is not positive

what are resources and curriculum — can ask Bronwyn

often mine pass on wrong info

youngsters in gay community are high risk

ask teacher training college

Alarmed at what teachers are saying. Would like to do something for them

will talk to son, daughters too

will talk to Nick, Auckland sexual health re this teaching

Maybe an action for accurate information to teachers

will bring resources book along for health sector

this from a general teacher and a few others

hundreds of starfish on beach wash up, threw one into sea. "Able to make a difference to that one" when asked by a friend who also said "so many, why bother?"

need to educate all population

need to educate teachers

maybe HIV is in the 'dirty' category

not surprised those that come to see you don't come back

people scared of HIV

cancer/diabetes is 'clean'

can do it in here — a proposal is an action

don't have to come up with a resource but to set ball in motion

actions

it is evolving — how do we go about it?

big task

need to give right education

e.g. catch HIV from sneezing

still have discrimination as teachers in schools are ignorant

area of sensitisation to HIV

friends, neighbours

individual families are supportive

family protects them

in my country people die because they don't want to admit they have HIV

in hospital people come and check to see how long you have to go

only at the end stages

fear comes ignorance comes from misinformation and creates stigma

e.g. mottled gown child misinformation because of fear

think media influence on how saw HIV in 80's

left an imprint on me

negative influence

negative thoughts

wonder about younger generation to see if have same view

think can use media to break damage been done

making our lives worse

Is she fit to be first lady in France because she has had 13 partners — big issue in Australian media — media ask is it acceptable?

doesn't matter how many partners — only takes one

XV

More programmes publically support from NZers

Removed from NZ doesn't face us directly

lots of aid for Africa

In NZ more Stigma for people in NZ

Beause may have no connection with sex

NZ puts it 'over' there may not be a reality not saying they shouldn't go to Africa

away from home

More acceptance in NZ of Africa

not in NZ

Poor people of Africa

Perhaps could be because more devastating in Africa rather than in NZ

Stigma and women living with HIV ③ 10 Sept 08

Def. of Stigma

AID foundation is aimed at one area

positive women development

how can I get funding, protocol to get round into schools

Youth liaison for + women

want to reach more youth as feel not being listened to

So don't come from an older stance

set aside special workshop for youth

We could share our actions with them for them to develop rather than duplicate

I would love to go round to every school and take the message

Our work could be background for this

Get teen to look at youth web site

get your persons interpretation

for booklet by HIV & AIDS

Not getting information to right people

perception is proportion % of women is high

Will ask CHB for resources

comments are best resource seen

midwives have high demand for pregnancy & HIV booklet from + women

easy to read, targeted at + women

medical profession like it

MOH booklets don't seem to get out

Action

get teen children to review MOH booklet

Family planning keen to work with + women

youth group

Will look at govt resource

Tremendous three

Stigma and women living with HIV 17 Sept 08

don't think about it

the session comes round really quick

life gets in the way

check in

missed doses so don't feel too good

see their resource on sexual health

getting more involved with + women

now back in my life as compared to when at uni when mixed with people who weren't HIV aware

Where do they get HIV and aids booklet from? NZAF booklet

look at MOH guidelines for sexual health

Will borrow DVD from school

actions

will do my action next week

taken me a while to get used to taking pills everyday

maybe feeling good so that is why missed

looking good dressed up today

need to have right information

look at teachers training college

poisonous blood

toxic and disease looking

scary looking

they want to do an educational resource

family planning are looking at making new resources

wanted to get hold of DVD to see how up to date it is

Bronwyn never replied to email

what do they do in schools

phoned teachers college given run around

spoke to health educator eventually

teachers need to acknowledge they don't know B/I will out

it is aimed at young people

dark looking family planning won't use

have other contact to follow up for this

NEED TO TARGET TEACHERS

plays into stigma

family planning won't use

HIV and AIDS booklet

if we did something it would be better than what they have

asked her what resources. Answer is nothing formal.

need to know a lot of information about HIV

dirty looking

confusing

family planning and public health nurses go into schools

phoned Francis kind and MOH Family Planning

There is nothing formal from teachers college

need to make make a resource

flyer

teenagers should write it

mw information feeds into stigma

written in adult format needs to be simpler

also I think it is a big deal

some schools don't some don't

MOM → ERO in 2007 review of sexuality Years 7 to 13

teachers working on info that is outdated and from their own source

did use NZAF programme in 90s

perception: not an issue anymore

student resource

teachers resource

don't do anything about stigma

don't pick out HIV education, part of sexual health

schools have policy around sexual health

strict religious schools might not do

will consult with community but don't

will always have copies of this

designed by youth for youth

say resources are old and reviewed in 2005

not read it yet

that it is not horror disease anymore

it is not so bad

where else daily treatable

shocking, not thinking about it

have website for more detailed info for both

Youth could develop own website (as feel + women site is boring) or youth links with links to/from other sites

NZ girls website

then come to + women retreat and give massages

supposedly an update organisation

disappointed in them

affects my view of organisation

shows where people are at

still in the fear stage

NZ college of massage

form for massage course says sign e declare communicable disease e.g. HIV

education not done in schools yet appears on forms !!!

Stigma

will approach UN and try to become an ambassador

send them an email

affects whole life, e family

problem is HIV different from STDs

Family planning don't want to seperate out HIV but treat in same way as STDs

wrote definition in draft copy on stigma

kids that have had are from around world young adults

might be interesting to find out why they say this question

Stigma and women living with HIV

definition

consider how reducing stigma needs to be focussing on not one thing but about many

+ women have facebook but don't know how to work it

where does stigma come from

poor knowledge reinforces stigma

misinformation

Stigma starts in the community

about being deviant, dirty

society puts labels

so don't have to bother about them

How does education tie in with Stigma

Counter balance by educating

plague, poisonous

need to inform what is HIV

linked in but they are distinct

do we want to stop Stigma?

not about condoms, or doors close

get rid of media circus about putting people on an island

Central node: **Stigma and women living with HIV 24 Sept**

Catch up/check in

Booklet

Stigma

Fantastic Four

- p2 needs more Talk between AIDS and HIV needs to be simpler
- parent says will tell them when have sex
- 20 year old thought cover dark
- I feel there is something not right with me
- Booklet is effective
- don't know I am +
- Continue getting feedback — talk to youth + worker
- Because people think if it is not a big deal
- Target is school age youth
- Intention is to make HIV scary
- Wonder if feeds into stigma
- Feel target too broad — youth not HIV and health professionals
- highlighted her fear
- maybe because of cost
- a nasty bug separate from person
- 17 and 20 year old girls 'horrid'
- She said "glad you kept your glasses on or people may associate me with you"
- She is paranoid
- So many people know you and know you are +
- We think HIV and us are one

- She interested in feedback from going
- asked Rashed at NZAF
- about bug not person
- looks yuck and nasty
- information good
- Why do you need AIDS on booklet
- Thought picture bit way off
- did it feed into stigma or fear HIV?
- went to fashion show and after party
- commented 'bad and nasty' first words 'yuck'
- 'drawings not positive at all'
- Feel nothing conclusive about feedback from booklet (all feedback was from girls)
- separate thing
- as a nurse wouldn't pick up booklet
- time gone so quick
- Been busy
- now week 4
- missing son who away for 8 weeks
- done a world tour
- wonder if daughter who knows you + sees it differently
- review/act still being formulated
- take booklet to a school and get feedback
- attended MOH review Health practitioner's assurance act
- did some homework
- week's been good
- Wednesday comes quick

- Great good, like pictures and spiky men can relate to virus and liked colour scheme
- p14 — half yellow
- p15 looks neg but positive
- p10 and 11 graph is confusing
- Don't know what is T-cell
- Format, size, amount of info good
- seen your poster at middle more hospital
- Big change
- Campaign has made me feel better
- Positive women org rep spoke to doctor
- doctor didn't get point of org
- "Just support women"
- feel people are normal after read book
- didn't think HIV disgusting
- Schools don't have a lot on HIV

- having fun is so important
- Been working working working
- positive thing was submitting work portfolio
- asked son about HIV teaching at school
- think son suspects
- helps them if they see you as strong
- two of my sons had worked it out and knew, but not about dad
- sometimes hard to fit fun in
- think children introduce fun into life
- think not having enough fun at moment
- 'Russian' time dark will not enough play
- chickened out of going into school to ask about HIV education
- tired and stressed out
- How much time do you need to play?
- Can you incorporate fun into what you do?
- associated with death
- fun is going for a walk, meeting friends, taking son somewhere different
- now son left — have a gap in life again
- more lonely now
- less happy than 20 years ago
- ex-partner/father figure for son is lonely
- Is a child a crutch
- made my life happy when he was at home
- contributing factor for him is not having children
- he is closed about his status
- might be why he is so lonely as no one else knows
- he thinks people won't accept him at all
- 1980s initially terrible wasting and picture of AIDS
- language thing NZAF works with HIV
- people in cancer ward so many people are dying
- haven't heard of anyone dying from HIV for a long time
- Booklet looks scary and feeds into stigma
- Should resource consider this
- If see booklet and it does it make you feel nasty/bad?
- HIV bug is bad it destroys my body. Differentiation between reason and fear is important
- What is Percum? he he ha ha :)
- how many youth know what pre-cum is?
- more stigma around AIDS than HIV
- afraid people might think he is gay
- visited public health
- Not got a lot on HIV mixed in with STDs
- If drop AIDS may be excluding people — if have AIDS still have HIV

Central node: **Stigma and women living with HIV project**

- perception this is a problem if I have HIV
- too scared
- Work out how to say we have the virus
- people thought shouldn't be working if HIV
  - would be nervous
  - would look for supportive environment
- Chefs, doctor nursing
- pricked self but wouldn't tell anyone
- found + women environment safe to come out about status
- There are laws but also indirect discrimination
- want her to say right things and be aware there are kids affected in school
- "Sex with Mrs DD"
- Made me want to touch everything
- Thought had tested, her husband wouldn't eat same food etc
- If flying, would it tell anyone
- Yes, but wouldn't discriminate as most people may find that have it
  - They think of death
  - a lifetime of medication
  - lot of people still in denial
  - really don't know
- Been thinking of this for a year
- I would want to talk to principle → principle talks to pupils about sex
- feel not jeopardising anything
- Seems lot of stigma in county with HIV
- Scared now, I support
- Find scary time when ill when living with sister
- Wonder if not in a working environment so disclosing not an issue
- Fashion Show organiser
- Principal is away till next term
- Chickened out of going to the school
- Scary → can I trust these people to treat me and my children right
- said 10-12 yrs life expectancy
- don't have fear that contagious
- have a normal relationship with husband
- had glass in foot made mess but don't have problem with plasters not happy with her choice
- Put a proposal together and was scared to give it to Rachel Hunter
- If you are not infected you are affected
- booklet feeds into stigma → rubs off on to person as well
- don't know assistant principle
- wanted to say I am HIV or I have virus of HIV
- won't share tweezers or razors
- felt very silly
- not surprising school visit is something to be wary about
- everyone knows somebody with HIV
- perpetuates stigma
- get the stigma with the virus
- feel son suspects, tell him have bad teeth so won't share ice cream etc → son doesn't really care
- found a stress for me working as a nurse
- want everyone to get to this stage
- Where do we get sense of so infectious
- scared of how people will respond
- even after 20 years still don't share but that button
- will use different spoon
- Not scared of disclosing
- want to come out when everyone comfy with it
- would't like to announce it
- looking forward to stage in NZ when people aware of HIV
- affected how I felt about nursing
- If people knew I was HIV ↓ would be horrible
- wouldn't do nursing now
- When disclose can't say
- 'only kidding, take it back'
- what if it is negative
- HIV common, would have kept it with family
- feel like have to have special cup
- fondu meal ↓ take fork out and put on plate, didn't share it
- comes from out there but internalise stigma
- It is me that tries to be careful and won't like ice cream
- don't want people to freak out if found out
- ask where razors either
- huge, that holds me back

Noticed this after what talked about regarding stigma of HIV

e.g. diabetes wouldn't be a problem

flicks up how different from other disease

the pressure of the 'secret'

attacks everything in life

not just a virus

It doesn't have to have so much power

I give it the power

influences and changes things

It's only a virus

Is this stigma or feeds into it?

So amazing couldn't say I need food to have pills because HIV

lovely the way my friend supported me

becomes so ingrained into way do things

worms its way into life

- told her and she shared wine glass I asked are you sure?

hard to pass on

Before never told my friend as don't see her often

She is a nurse

I don't have sense of being infectious to everyone

no need to share everything with everybody

forms need to be tidied up (questionnaire)

to say this is the end

winding up

what will people need in terms of process for closing?

how do you feel

Sad to miss the others

purpose

feedback

tremendous trio

a threesome is good

Stigma and women living with HIV   31 Sept

summary

what's come up over last 4 weeks for you

good history and supportive of me after raped

more about what I am feeling inside

what is this about? Not how contracted it

don't share food etc

take the power out of it

worried about passing it to others

Check-in

Had medical visit today

amazing safe place to be

saw mum and dad at weekend

dad not doing so good

son at home so big and manly huge man

Had a nice week

ex been communicating with him

Breezy week

How do you tell yourself?

Son fell out of punt and lost glasses and watch

forgot stuff and lost stuff today

School holidays

Important for me to say I have HIV virus

Thinking you are worrying about how to tell others

laughed at this. son is sensitive so need to be careful (Slapstick sense of humour)

need to get away from here, change of environment

Been thinking about new terminology

'I have HIV virus' doesn't sound right

I have the HIV virus. Will people think what does that mean?

Stopping me from connecting with virus

better than 'I am...'

how do we name it to ourselves?

You can call it what you like. But where do you put the emphasis

really looking forward to seeing him

the living with HIV

'the' sounds funny

not come up with anything succinct so can say differently, 'I am...'

Why should we say this? Don't say, I am breast cancer'

Stigma and women living with HIV (2) — 31 Sept

they see the virus they see normal people

easier for others who not HIV

because 'I am HIV'

person who does not have HIV has knowledge but is not mixed with emotions

easier for others to kiss you rather than you kiss them

we carry what others might be thinking

know about HIV

emotional charge is mixed up

Knowledge and emotional connection is mixed together

language we use

not ready for taking stigma away (big step)

Maybe need to focus on what it means to be me rather than 'I am HIV'

first steps to define ourselves

we define by job etc so difficult to define ourselves

Maori define by who you know — different way of connecting

have difficulty filling out forms

Should write 'Being (name)'

make up a name to describe what we do

reflects 'you are what you do'

ask where is your accent from?

how do you take stigma away

success of depression campaign with rugby player

get a feel for a person

ask 'what do you do with your time'

with other people's reactions

can't test it as when do can't go back

people choose how to answer it

Judgement

Shame

rejection

internalisation of stigma

whats come up over 5 weeks for me

very strong. I question how much is out there and inside me

but still have a physical relationship

I hate condoms

had more than one person who wanted me

had thought nobody would love me

husband knew 2 days after he met me about HIV

can separate it out

Sex

never felt the poisonous

mine came from a rape

but don't have children

think there are different ways of living

say to others people will love you when come with HIV and believed it for them but don't think this is me

we know this won't pass it on

have fear of rejection

good to know that others felt the same

this is how I lived

I have tested on an external level

Still have internal stigma though

Couldn't have a man kiss me

no one wanted me, no relationship has happened

feel like the black widow spiders that gobbles up the partner

too difficult to think about

haven't had sex for 14 years

HIV is about sex don't want to have sex anymore

over thinking a lot of others

it is hard for me how is it for someone without this knowledge

feel my blood is poisonous

sad to say this about yourself it is the virus not the blood

Central node: **3 Sept — Stigma and women living with HIV ③**

- make a collaborative enquiry group
- What would happen if no recorder or a man in room?
  - Could we go deeper?
- What is showing is a need for a support group
- suspect people found it very hard to see drawing and emotional
- hard to get people to come along here
- took 3 months to get people to come to this
- Did a talk and instead said I am... and have been living with HIV for 20 years
- what a difference to "I am..."
- in England happened to be my primary school teacher
- Someone knew someone
  - it is a bonding question
- wind up and wind down
- we can continue with what we found helpful
- **Closing**
- **When Started**
  - Thought already spoke about this but have found that did something
- took away the power of the secret
- how much we internalise. Didn't know others felt about sharing cups
- walks alone with HIV
- **findings/reflections**
  - refrain bad language and say we met and talk
  - support for other diseases is there
- Internalising we knew but still worried
- discovered misinformation with young people
- teachers were misinformed
- give feedback to NZAF re booklet
- collaborative enquiry
- not a therapy but could be therapeutic
- how has the process been
- to we do this to ourselves?
- Family planning want to take back to women, take them into schools, into action
- made me have doubts as struggled to connect actions
- when met man who wrote book different to what saying in book
- only people with HIV know this
- fits with stigma feeds into it
- almost a support group
- Thank you for your commitment
- could have done first 3 weeks as just talking
- Initially thought 5 weeks a long time, feel now way too short
- don't realise how much need something like this until have it
- **Before HIV**
  - was self-conscious and insecure
- HIV given me a reason to feed into insecurity
- getting older feeds into insecurity → my butt sags
- none connected to HIV a way of finding excuse
- far more constructive than support group as looked at making it a positive better way
- spoken things not spoken to anyone
- been really good very safe
- reluctant to come into HIV buildings in the past
- grateful for whole process, very positive and thought provoking
- supportive, affirming
- the safety can talk about things
- change comes from reflection. It is an action and he should be told
- from reflection will small act
- huge consequence in changing our language
- process highlights how stigma gets into all parts of life
- find complexity of HIV and stigma interesting
- on reflection may have pushed actions
- need to summarise how deal with those actions
- feel have achieved something
- feel done a lot
- got actions
- worried that 5 weeks not long enough
- will miss the meetings
- makes me feel stronger in the world
- not alone
- surprised at how it has worked
- been valuable to me as a participant
- feel been through a process that can be written about
- what can cover and how can wind it up at the same time
- different from filling in a questionnaire which benefits researcher only