

# NAVIGATING HIV

A Study of Life with HIV/AIDS



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Inspiring Innovation and Discovery

*Yes, but where does the time for life come in? HIV becomes your whole life. If you're spending all your time researching drugs, researching treatments, visiting doctors, and nutritionists, it becomes your whole life. Where do you have the time to live anymore?*

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Finally, there would have been no study were it not for the individuals who agreed to participate. This was a project that asked for more than an hour or two of people's time. We were asking for, and received, a commitment to sustained contact over three years. We asked for, and received, answers to questions that were not always easy. We asked for, and received, reflections on experiences that must have been difficult, and in some cases, painful to revisit.

Rose Weitz, an American sociologist who has done research on people living with HIV/AIDS has written that many individuals choose to participate in research projects because they consider the interviews they give as legacies. They hope their stories will benefit others. We are grateful for the gifts of time, honesty, insight, interest and enthusiasm that our participants shared with such generosity and spirit. Our hope is that we have captured their journeys with HIV/AIDS faithfully, and that in doing so we are providing others with HIV/AIDS, service workers, health care workers, researchers and policy makers with a report that they will find illuminating and useful.

# EXECUTIVE SUMMARY

This report summarizes findings from an in-depth study of the lives of people with HIV or AIDS. Our goal in conducting this study was to examine how people living with HIV/AIDS understand and manage their health and health care. We began by interviewing 48 people with HIV living in the Hamilton area, and continued to interview as many of these as we could 3 more times over 3 years. Here are some of the things we learned.

**MANAGING INFORMATION:** People with HIV are constantly making decisions about whether to tell people about their HIV and their health. Most are concerned to some degree about the possible negative or stigmatizing reactions of others. The stigma surrounding HIV has diminished over the years, but it is still an important concern for respondents.

Stigma does not tell the whole story about disclosure and secrecy. For example, some people decide not to disclose their HIV status to others to protect them from the burden of worrying about the health of the person with HIV.

Decisions about disclosure often influence health care decisions, and health care decisions can have an impact on how they manage information about their HIV. Also, one decision about disclosure leads to a series of many smaller decisions, like whether to give updates about their worries, new aches and pains, or changes in treatment.

**AGING WITH HIV:** With the advent of more effective treatments many people with HIV are growing older than they had initially anticipated. HIV can make the aging process a more positive experience, but it also presents unique challenges.

Growing older is often seen as a triumph or a victory over HIV. Having HIV means that issues related to mortality may already have been faced, making aging a less frightening experience. Having HIV means that certain preparations have been made for 'slowing down' so that aging does not require major adjustments. Aging can represent a distraction from the constant worry about HIV. Aging gives many PHAs a sense that they are just like everyone else their age, facing many of the same dilemmas and issues.

Among the unique challenges are the following. Many are growing weary of the endless ups and downs, changes, and uncertainties having lived for a long time with HIV. HIV can make it more difficult to make sense of bodily changes and symptoms. Aging has also left some people with regrets about the decisions they made earlier in their illness, not anticipating that they had many years yet to live. HIV, with all its uncertainty, makes it difficult to look ahead and plan for the future.

**MEANING OF MEDICATIONS:** Medications are understood by respondents in complex and often conflicting ways. For many, medications were both a sign of hope and a source of resentment and frustration. Medications were often perceived to be a lifeline, even in the face of doubts about their effectiveness. Taking medications was also seen for many as a means of being responsible for one's health.

HIV medications also often elicited anger, fear and resentment either because of the side effects that they might cause, or because they signify personal failure in maintaining health. Some respondents wondered if they might be doing more harm to themselves by taking medications. People with HIV/AIDS felt that this dissenting view of medications-as-harmful was not often welcomed by friends, family or health professionals.

**PHYSICIAN AUTHORITY:** The importance of physicians in managing HIV was a predominant theme among respondents in our study. Working with physicians involves a constant push and pull of authority, expertise and trust. Physicians have authority over access to services and benefits. Many respondents viewed their physicians as allies in helping them to gain access to treatments and services. Conversely, others viewed their physicians more as gatekeepers who control access to resources. Respondents often felt frustrated when they were unable to gain access to the resources that they felt they needed.

Physicians were also seen to have expert authority in managing HIV. Some people preferred to rely upon their physicians' expertise when making health care decisions, whereas others sought partnerships where their own expertise about their health carries equal weight. The division of authority between physician and person with HIV/AIDS did not remain static but changed over time in relation to factors like health status and length of infection. There is often tension between people with HIV and their physicians, frequently arising from a perception that the physician is uncomfortable making any compromise in what they view as the best medical treatments they have at their disposal.

Physicians were seen to have moral authority by people with HIV/AIDS. This perception was expressed positively in the form of reverence or negatively in the form of suspicion or resentment. Respondents often felt judged by their physicians over matters that had little or nothing to do with health care.

**RESPONSIBILITY AND HIV:** People who are infected often feel that they have to struggle to find and maintain a comfortable identity as responsible and productive citizens. At this point in the history of the epidemic there appears there are greater expectations placed on people with HIV/AIDS than others to be morally responsible individuals. This can lead many PHAs to maintain a sense of themselves as moral by strictly following medical advice, serving in a volunteer role, abstaining from sex, or participating in clinical trials.

Many people with HIV/AIDS feel that they are personally responsible for their health, and carry a sense of self-blame for having contracted HIV infection. Managing health by following medical direction and expectations is one way that respondents can live as ‘good people with HIV/AIDS’. However, the emphasis on individual responsibility can be experienced as isolating and fuel feelings of guilt and inadequacy.

**IMPLICATIONS:** This study explores the relationship between biological disease, respondents’ personal lives, and historical context. We show that the illness trajectory of our respondents was shaped by both factors in their personal lives, and broader historical shifts.

Navigating HIV means carefully and thoughtfully responding to changing biological realities, aging bodies, developments in medical technology, evolving understandings of HIV, the unfolding of people’s relationships and work lives, and even, shifting ideas of roles and responsibilities of individual citizens and the state.

# 1. INTRODUCTION

This report is about people living with HIV/AIDS (PHAs). We set out to explore how a group of men and women perceive and manage their health in the face of an HIV/AIDS diagnosis. We were interested to know how they used medical treatments, if indeed they choose this route, or whether complementary therapies or self-help had any role in their management strategies. We were curious about the impact of new anti-AIDS drugs. We were also curious about issues and problems that PHAs confront in looking after themselves.

It is impossible to talk about health decisions apart from the larger context of people's lives. Whatever health decisions PHAs make, even situations where they appear to be making no decision at all, their actions play themselves out against a backdrop of families, friends, relationships, work situations, living arrangements, finances, location, stage of life, stage of infection and so on. Furthermore, this backdrop is constantly changing. Symptoms appear and disappear, health ebbs and flows, people and contacts come and go, new family and work situations arise. This led us ultimately to the imagery of navigation that we used to frame this report. While most of the original health-related questions we started out with are addressed within these pages, the report is about more than health. It is about life with HIV/AIDS and how PHAs navigate a course for themselves, continuously taking stock of where they are, where they have come from, and where they might be going.

## OUR RESEARCH APPROACH

Before turning to our findings, a word about how the study was conducted. To capture the experience of living with and managing HIV/AIDS over time, we used a longitudinal study design. That is, rather than relying on one-time interviews, we conducted a series of four interviews with the same group respondents over the three years of the study (2001-2004), at approximate 8-month intervals. Ethics approval was obtained prior to the start of our study.

Respondents were recruited in a variety of ways. We wanted to recruit a diverse sample of people living with HIV in and around Hamilton, so we placed ads in several newspapers and local publications such as the *Hamilton Spectator*, the

*Examiner*, the *Vien*, and *Xtra!* We also put up posters in clinics and other locations throughout the city: the Hamilton AIDS Network, Women's Health Services, the Hamilton Friendship Centre, the North Hamilton Community Health Centre, the Special Immunological Services (SIS) Clinic at McMaster University Health Centre, the Van Needle Exchange and Gomorrah Books, a gay and lesbian bookstore in Hamilton.

Our advisory committee, made up of individuals representing the Hamilton AIDS Network and the Van Needle Exchange Program was helpful in setting our research questions and in recruiting participants. They shared information about the study with the groups they have connections to and more directly in some cases, put us in touch with potential respondents.

Once we had an initial group of respondents, we used snowball sampling to generate additional names. That is, we asked respondents to pass on our names and numbers to others they knew who might be interested in participating. As a result of this process, we started the study with 48 respondents. Attrition is a major risk in any longitudinal study, even more so in studies where there is instability in the lives of participants. We were generally pleased, however, with the number of respondents we were able to retain. The second set of interviews included 41 respondents; the third, 30 respondents; the fourth, 29 respondents. One respondent died before the study was completed.

Our agreement with respondents was that the interviews would take place in a location of their choosing. While some preferred to be interviewed in their homes, others elected to do the interviews either at the offices of the Hamilton AIDS Network, in a public place (ie. coffee shop) or at the university. Most of the interviews took between 60-90 minutes. In each case we received permission to audio-tape the interviews. All of the interviews were then transcribed. Each respondent received a subject fee of \$50 per interview. The purpose of the subject fee was to compensate respondents for their time and in some cases travel expenses, but also to recognize in some way the long-term commitment they made to the study.

The interviews were largely open-ended. For each set of interviews, a guide, rather than a fixed questionnaire, was used to orient discussions with respondents. In keeping with the grounded theory tradition that we used to do this study, our

analysis of the data began as soon as the first interview transcripts were produced and continued through the data collection phase of the study. Throughout the interviewing process, we met as a team to discuss what we were hearing. As the study proceeded, our discussions began to focus on certain themes. These themes were reflected in subsequent interview guides.

## **LONGITUDINAL NATURE OF THE STUDY**

We found that there was significantly greater openness among respondents as the interviews proceeded. Participants discussed their situations in greater depth, filled in gaps, provided more detail and nuance in their accounts and in general, shared more of how they felt about things rather than simply describing events and situations. The data from the interviews became progressively richer, more personal and more revealing. There is no doubt that the increased openness, and perhaps the low attrition rate as well, were related to the trust that developed between interviewers and respondents over the three years the study took to complete. However, if respondents were able to talk about their experiences with greater clarity, honesty and depth as time went on, this pattern was also due to the opportunity that longitudinal studies present to reflect on issues.

The first of the interviews, conducted in the summer of 2001, was the most broad-ranging. At this stage of the study our interest was in getting a general sense of who our respondents were and how they were managing their HIV/AIDS. In addition to getting basic demographic information, we asked questions relating to what concerns they had about their health, how they kept track of how they were doing, whether HIV/AIDS had changed the way they think about health, what they were doing to deal with their HIV/AIDS, what treatments – both conventional and complementary – they were receiving or had received in the past, and their involvement with health care workers and AIDS service organizations.

During the second and third interviews more pointed questions were asked about how respondents situated themselves in terms of some trajectory, how they handled letting people know about their HIV, what they thought it meant to be a “good PHA,” and how they felt about changes in their body. We continued to provide opportunities for respondents to discuss more generally how they were doing and how things had changed since the last interview. The final interview combined updating with questions that asked respondents to reflect on their participation in the

project. We asked them what had drawn them to the study. We also asked whether the interviews had any effect on how they thought about health or how they managed their health care.

Even one-time interviews are said to be “perspective-generating.” They have the effect of causing individuals to step back and think about various dimensions of their experiences. Put in a situation where they are asked to talk about those experiences, they become more overtly conscious of how and why they do the things they do or think the things they do. This type of reflection often continues well after the interview is over. A major advantage of longitudinal studies is that there is the opportunity for the researchers to follow up on issues raised in previous interviews and to benefit from respondents’ more careful reflection.

After the first interview, respondents in our study had a better sense for where we were going. Many made mental, and sometimes physical, notes of points to talk about, thoughts or insights they had occurred to them, and changes or events that they felt we might want to know about. They were eager to pass these on. Whether the respondents actually took this type of long-range view of their experiences or not, the longitudinal nature of the study allowed us to develop a more dynamic view of the day to day reality of their lives. Whether their circumstances improved over the course of the study, deteriorated or stayed the same, our more regular conversations allowed us to see the ups and downs along the way - in terms of their health, social lives, housing circumstances, or work situations and relationships with both significant others and health care professionals.

## **OUR SAMPLE**

Of our initial 48 respondents, there were 35 men and 13 women. Among male respondents, 26 were gay and 9 were heterosexual. Among female respondents, 11 were heterosexual, 1 was lesbian and 1 was bisexual. Respondents ranged in age from 20-64 years. Three respondents were in their twenties, 18 in their thirties, 21 in their forties, 4 in their fifties and 2 in their sixties. A range of ethnocultural backgrounds were represented, including (using identifiers that respondents themselves used): Aboriginal, African, Canadian, English, French-Canadian, Hungarian, Irish, Italian, Jewish, Polish, Scottish, WASP, and White. The vast majority (40) of respondents lived in Hamilton. The remaining 8 lived in neighbouring communities such as Brantford, Cambridge, Rockwood, Niagara Fall, St. Catharines, and Welland.

In terms of educational background, 11 had received a post-secondary degree, 8 had some post-secondary education, 16 had completed high school, while 13 had less than a Grade 12 education. A majority of respondents (36) did not work, while another 6 worked on a part-time basis only. Six respondents worked full-time. These employment patterns were reflected in annual household incomes. A majority of respondents (34) lived on less than \$20,000 per year. Only 4 had an annual income of over \$40,000. The remaining 10 had incomes that fell in between \$20,000 and \$40,000. The most significant sources of income were Ontario Disability Support Program (ODSP) and long term disability insurance. Five respondents received welfare or family benefit payments.

The length of time respondents had been living with HIV varied widely, from 20 years (since 1984) to less than one year. Nineteen respondents had been living with HIV since 1990 or earlier. Sixteen were diagnosed between 1991 and 1995. Thirteen were diagnosed after 1996. The vast majority of respondents (45) described their health at the beginning of the study as average, good or very good. Only 3 described it as poor. However, as all of the interviews, including the first set showed, the way individuals characterized their health was not necessarily a good reflection of the health difficulties they were experiencing. Among those who described their health as good were individuals who were dealing with fairly serious health problems, both HIV-related and not. Several respondents were also struggling with drug and alcohol-related problems.

## **OVERVIEW**

We have organized this report according to five main themes that emerged from our analysis of the data. Each of these sections focuses on a particular aspect of living with HIV, and each captures the idea of the constantly shifting and dynamic quality of this process. In Section 2 we discuss how respondents manage information about their HIV infection and their concerns about stigma and discrimination. Section 3 looks at issues relating to aging and HIV, outlining some of the particular concerns and advantages of respondents. Section 4 examines how respondents understand the place of medications in their lives and Section 5 considers their relationships to physicians. Section 6 examines some of the moral considerations involved in living with HIV. In the conclusion of the report we briefly discuss how our study helps us understand various dimensions of the trajectory of HIV and some implications of our findings.

## 2. MANAGING INFORMATION ABOUT HIV

HIV/AIDS has been one of the most highly stigmatized health concerns in recent years. The stigma and discrimination that surrounded HIV were central a feature of the epidemic in North America and elsewhere over the past two decades. The popular press in the 1980s and 1990s often carried stories about people living with HIV who had lost their jobs, were rejected by friends and families, and were thrown out of their housing.

Concerns about stigma led most people living with HIV/AIDS to weigh carefully decisions about whether to tell others about their HIV infection. Research in the 1980s and early 1990s by social scientists like Peter Conrad (1986) and Rose Weitz (1991) understood disclosure and secrecy issues largely in terms of stigma and stigma management. By the mid-1990s, Barry Adam and Alan Sears (1996) published their research on living with HIV, which examined disclosure issues in some detail. A lot has changed since the time of these previous studies. Much of the earlier hysteria surrounding HIV has diminished, and with the advent of more effective treatments, more people are experiencing HIV as a chronic illness.

Given changes such as these, we started this study assuming that stigma, disclosure and secrecy would be considerations for our respondents, but that they would no longer loom as central concerns in their day-to-day lives. Yet, as we conducted our interviews, respondent after respondent told us they were concerned about the negative reactions of others to the news of their HIV infection, and they described the great care they often took in managing information about their health. In this section of the report, we examine our respondents' deliberations about whether to tell people about their HIV and their health.

### STIGMA REMAINS AN IMPORTANT CONCERN

Our respondents all expressed some degree of concern about the negative reactions of others. These concerns were important considerations when deciding whether to tell others about their HIV infection. A number of respondents reported experiencing stigma first hand. One man described an incident during a supervised visit with the children of his girlfriend:

*The Children's AID Society were totally fucked up. We were eating carrots. We were sticking the carrots in the same dipping thing and the woman (supervising the visit) freaked out. They didn't know what was what. They went as far as to test the daughter for HIV.*

For the most part, the stigmatizing reactions respondents described were often indirect and relatively undramatic:

*If you ever had close friend all your life, and all of a sudden that friend started acting weird. They weren't coming over for dinner as often. The phone calls slowed down. The kids weren't playing together. You begin to wonder why.*

Still, stigma remains a concern. Another respondent observed, "HIV is not as mainstream as everybody might think. They try to think it is – that everybody's informed, that everybody's wearing little red ribbon." HIV infection continues to be associated with gay sexuality, so homophobia and heterosexism continue to shape the experience of living with HIV for gays and nongays alike.

For many of our respondents it is the concern about the *potential* for stigma rather than direct experience with being stigmatized, that made them careful in managing information about their health. Their decisions about disclosure were shaped more by what *could* happen than what *had* happened to them.

*I did know someone who had AIDS. He was one of the first people I knew who had AIDS; he was the first, actually. He couldn't even get a nurse to touch him in a hospital. His mother was having to take on the Board of Directors at the hospital to say, "This is obscene! No matter what he's got...whatever is wrong with him. He's a human being. So take precautions then. Wrap yourself up in gauze if you have to, but touch him." ...Two years later, you're there yourself and you think, "I don't want that, so I'm not telling anybody.*

Stigma does not always lead people to be secretive about their HIV. Concerns about stigma can lead some people to disclose out of a desire to change the social climate and lift the silence that surrounds HIV. One respondent spoke of making disclosures because he recognized that his fortunate circumstances were not always shared by others with HIV: “I ’m very lucky because I can disclose and I don’t have much to fear in the way of discrimination. My housing is secure and my work is secure. I’m very public about it so my family knows. I know that’s not the case for most people. I’m lucky enough to be able to disclose, so I do generally.”

Our interviews suggest that the stigma surrounding a diagnosis of HIV has changed in at least one regard. A few respondents noted that those with new infections face greater blame than was the case in previous years. A consequence of messages to be responsible is that people can now be held individually responsible for acquiring HIV in a way that was not as possible prior to public education campaigns that stress individual responsibility. This seems particularly true for gay men:

*I think as a movement we’re not nearly as supportive for new infections as we used to be. There’s a lot of judgement. If you’re a gay man, you should know better.*

## **DISCLOSURE AND SECRECY ARE ABOUT MORE THAN STIGMA**

Many of our respondents’ decisions about disclosure and secrecy were driven by concerns relating to stigma, but this does not tell the whole story. Respondents’ decisions about whether to tell others of their HIV status may also be motivated by considerations that have little or nothing to do with stigma. Decisions not to disclose can be motivated by a desire to protect others. For example, many respondents talked about not telling family or friends because they didn’t want them to worry. Parents, in particular, talked about wanting to protect their children from distressing news. Decisions to tell may also be motivated by the same desire. A mother talked about why she told her teenage son before he left home,

*I just thought, well, if he knows, then he has a choice whether he wants to be around me or not. But I didn’t want him going through a life of regretting that I didn’t spend those years with mom cause she never told me.’*

Another mother expressed a similar sentiment about her daughter:

*The last couple of months, things have been going downhill health-wise for me. It scared me, and I didn't want something to happen to me and for her to find out through somebody else. Because then she has to live with that for the rest of her life. And I don't want her angry at me and upset with me. She would probably look at it as I didn't trust her enough to tell her the truth.*

In a more self-protective mode, some respondents didn't want to have to support others in their reactions to the news of their HIV status – these respondents felt they had enough to deal with without taking on the role of supporter and educator of people upon whom they counted for support. One man talked about how he often ended up having to take care of the other person following a disclosure:

*It's annoying that you're putting yourself in emotional risk and you're throwing yourself out there, and yet, you're the one that has to take the lead, you have to take the risk, you have to decide how you're going to say it, you often times have to support them because they're feeling badly ... So you have to comfort them and say, 'No, it's fine.'*

Other respondents simply didn't want to add 'weight' to their relationship, or deal with worried 'how are you?' questions. Some disclosures seem motivated by a desire to get it over with to avoid future uncomfortable moments. One respondent who worked in an AIDS organization described how he sometimes made disclosures to avoid the potential for future discomfort: "Because I'm so public, it's quite likely that they will find out at some point. So if I think that I might know them or run into them socially, I'd rather just tell them up front."

Similarly, decisions to disclose may be driven by factors unrelated to stigma. Some respondents disclosed to explain why they were not working or why they needed to take time off work. One respondent talked about how he needed to tell friends because he had to explain why he often threw up in their presence. Others disclosed to manage interpersonal relationships, perhaps to develop closer relationships with

others or to lift the burden that often comes from keeping something important from others. Stigma may be a factor in these moments, but it is not necessarily central.

## **DISCLOSURE AND SECRECY ARE ONGOING CONCERNS**

Disclosure and secrecy are not one-time decisions. Each disclosure can create the need for continued interactional work, such as caring for others as they come to terms with the news, dealing with their crying, calming their worries, answering their questions, or providing education. Decisions to disclose can bring a seemingly endless series of related revelations. Having revealed their HIV status, respondents needed to consider whether to disclose new aches and pains, the worries that kept them up at night, or their thoughts about their own mortality. Decisions to be secretive can also generate ongoing interactional work. They can create a web of falsehoods that requires work and vigilance to maintain. There is an ongoing need for self-monitoring to avoid inadvertent disclosures, and an ongoing watchfulness of others to see if and when they might be ready to receive a disclosure.

Disclosure and secrecy issues are not static: they change over time. Respondents need to reconsider questions of disclosure as a result of changing relationships, new jobs, or moves to new locations. One respondent talked about his need to start making new disclosures for the first time in years, as he is now single and meeting new people. The change in his relationship status disrupted his routine for dealing with information about his HIV status.

All disclosures are not equal. As Adam & Sears (1996) described, the context of the relationship is important. Questions relating to disclosure often feel most acute with regard to family relationships where there is more pressure to tell, but more to lose if things do not go well. Family disclosures often come with a greater chance of judgement. Disclosure in friendships are often a bit easier, because there is a different set of expectations at play; the norms of friendship kick in. Respondents may feel as if they are betraying close friendships by not telling, as one does not hide important details from friends. At the same time, friends are expected not to be judgmental and to reciprocate in the friendship by displaying support and caring. There is a difference between expectations of nongay and gay friends. Gay friends are often perceived to know more about HIV – so they require less explanation –

and they are often expected to provide more immediate and unquestioning support than nongay friends.

Telling sexual partners can be complicated by questions of infidelity and by questions about whether one is morally and legally obliged to tell sexual partners. Again, concerns and expectations around sexual partners of gay men are different. HIV/AIDS is more present in the lives of gay men, so direct disclosures to sexual partners may feel unnecessary. But even here, different kinds of relationships bring different disclosure considerations. One gay man reported:

*If I meet somebody in a casual sex environment, I will have likely disclosed to them. Or if I think that I would like to see them again, then I will disclose quickly and easily. But if I meet somebody socially, like a tea party or something, my status may or may not come up. And so, if I get to the point where I want to start dating, and I haven't disclosed then ... The more you wait, the more risk there is. I would probably disclose as quickly as possible but there will be a different level of emotional risk if it's somebody that I think I might actually be interested in dating.*

Disclosing to other people with HIV/AIDS can be relatively easy, and can provide new sources of support, information, and understanding that comes from sharing a common life experience. But some respondents expressed a reluctance to identify too closely with other people with HIV/AIDS out of concern that HIV not be thought to define their entire existence.

Disclosure in public for some is also relatively easy, as it comes, paradoxically, with a sense of anonymity. Even some respondents who have made very few personal disclosures routinely talk to groups of students. For these individuals, the social and personal benefits of changing the attitudes of others, finding meaning, or reducing isolation, appear to outweigh the potential costs of such disclosures.

## DISCLOSURE AND SECRECY RELATE TO HEALTH CARE DECISIONS

Disclosure and secrecy considerations can have important implications for healthcare decisions – just as health care decisions can have important implications for disclosure and secrecy. At least one of our respondents had not told her physician about her HIV status because she was concerned about his reaction. She also did not trust that his office staff would handle the information confidentially. As a result, she might not have received the best of care. Other respondents chose to seek health care in Toronto to minimize the possibility that their personal information would not get out. Conversely, some respondents told their health providers to ensure they received good health care. One woman, for example, described the difficulties she experienced in getting good eye care when she did not tell her doctor about her HIV:

*I didn't have any eye care and my vision started deteriorating again ... I went to see my general practitioner. I told him that I wanted to see an ophthalmologist and he said, "No." He said that instead I should see an optometrist, that I don't have a problem with my eyes. I told him that I don't need an optometrist, but he said no. I went to see an optometrist and he said, "Your vision is okay." I can see well, but deep down inside, in the back of my eye, there is a problem. So, I told the optometrist, "You're saying I'm okay, but I need to see an ophthalmologist." He said, "No".*

Conversely, a couple of respondents decided not to tell a health provider to ensure better care. She had previously disclosed her HIV status to her dentist, and felt the care she received was not very good, as a result:

*The new dentist that I am dealing with is doing amazing things because I believe he thinks that I'm going to live a long life. There's no reason to think that I'm going to die, where my old dentist did, so he didn't do the work. He did shoddy work, cheap work. He used cheaper products. He said, "Oh, that's just a surface thing. Don't worry about it." That 'don't worry about it' is putting me now into eight appointments with a new dentist to try to repair everything. So there's a lot of downfalls to disclosing, if you will.*

The need for medical care may change the deliberations about disclosure because respondents have to account for medical appointments. Starting a new course of treatment may complicate decisions about disclosure in that respondents may experience side effects, such as fatigue or diarrhea, that may need explaining. One respondent described a situation with her daughter, who had not been told about her mother's HIV:

*When she's at her dad's, she worries nonstop about me. And that's because she's watched me throwing up. And I can't prevent that. I can't. There's no way in hell I can prevent that. I try and try. They'll knock on the bathroom door. They can hear me. I say, 'It's okay, I'll be fine.' 'No, Mommy, you're lying. I can tell when you're lying.' So then we have this big controversy on, 'Don't lie to me, tell me you're sick. I can hear you're sick, Mom. Don't tell me you're all right, 'cause you're not all right.'*

Body changes caused by medications, such as weight loss or lipodystrophy, may also need explaining to friends and family. Because of this, some respondents did not begin a new treatment, while others made disclosures that they might not have made otherwise.

Medications also present challenges to respondents who have not disclosed their HIV to friends and family. Their medications may need to be hidden. Pills need to be put into less suspicious looking bottles and they may need to be taken surreptitiously. Faced with such choices, some of our respondents chose not to pursue certain treatment options. And for at least one respondent, a disclosure was made to explain the appearance of numerous bottles of medications.

Treatment progress also can factor into disclosure decisions. Unsuccessful treatments may lead people to disclose to explain why they are getting sick. Even successful treatments can affect the way people manage information about their HIV status. One man talked about how he has been healthy for so many years that his HIV recedes into the background in much of his day-to-day life. As a result, he has not told some people who otherwise would likely have been told.

## CONCLUSION

Twenty years into the epidemic, stigma continues to be an important concern for respondents, but it is simply one of many factors that shape their decisions on how to manage personal information about their health status. We need to remember neither to overestimate nor underestimate the place of stigma in people's lives and in their disclosure decisions. Limiting our understanding of disclosure and secrecy to stigma management is too narrow.

Disclosures are not just about HIV status, they are also about moral status. A disclosure may be an assertion of being a loving spouse, a close friend, a protective parent, a trustworthy sexual partner, a good patient, or a contributing citizen. Indeed, disclosures are often told as morality tales. Respondents' accounts of their decisions whether to disclose their HIV status are often implicitly couched in moral terms. Sometimes their accounts are more explicitly framed. One respondent propped up his heterosexuality by emphasizing his drug use to allay concerns about his sexual preferences

Similarly, accounts of respondents' decisions not to tell some people are also framed in moral terms. They may not tell in order to protect others, to respect their beliefs, or to avoid distressing them. Again, it's more than just about HIV status. While this point goes beyond the confines of our study, respondents had a moral evaluation of how people received disclosures, particularly friends and professionals.

Decisions about disclosure and secrecy are made in the messy and changing contexts of people's lives, and over the course of a changing epidemic. The findings from our interviews remind us that disclosure and secrecy decisions are not static: previous decisions may be reconsidered as respondents' health changes, as they begin new treatments, as they become better informed, or as they enter new relationships. Questions relating to disclosure and secrecy can take a toll over time and are never far away. Respondents talked about their weariness in constantly having to attend to who knew, who to tell, whom to tell, what to tell next. As we discuss in the next section, this becomes more significant as people are living longer with the knowledge of their HIV status.

### 3. AGING WITH HIV

Since the beginning of the HIV epidemic, patterns of HIV progression have changed dramatically, particularly in recent years. While long-term survivors were once relatively rare, HIV has increasingly become for most people, a chronic, long-term disease. This is largely due to the development of effective anti-HIV drugs (antiretrovirals) which, at least in the developed world, has meant a more optimistic prognosis for many individuals diagnosed with HIV/AIDS. It has also meant that more people with HIV/AIDS are growing older.

According to Health Canada's Centre for Infectious Disease Prevention and Control (2003), as of June 30, 2003, 7,378 (40%) of the 18,929 AIDS cases in Canada were reported among individuals 40 years of age or over (6,881 men and 499 women); 2,222 of these people were age 50 or more. As well, about 10% of new HIV diagnoses are among people over the age of 50. Health Canada (2003) notes, "As our society ages and persons with HIV/AIDS live longer due to improved medical treatment, it is likely that HIV/AIDS among older adults will become a greater issue" (p. 24).

This trend is reflected in our study as well where 26 out of 46 respondents (57%) were 40 years of age or older. While it is clear that many more people are experiencing "aging" with HIV/AIDS than once was the case, few studies have looked specifically at what that experience is like. HIV/AIDS continues to be seen primarily as a young person's disease and many of the assumptions about what it is like to live with HIV are ageist. Older adults have been for the most part invisible, not only in scholarly work but also in program and service planning and provision, and in policy formulation (Health Canada, 2003, p. 24; Nichols, 2002, p. xvii). This study, with its relatively high proportion of individuals over 40, offered a valuable opportunity to begin to explore the issue of aging and growing older among people with HIV/AIDS. In this section, we focus on the predominant themes that emerged from our data in relation to aging with HIV.

#### **OLD AGE AS A TRIUMPH**

Though advances in HIV treatment may have changed the reaction to a diagnosis of HIV/AIDS, most of the individuals in this study had been diagnosed at a time when

the prognosis was grim. They had heard the news as a death sentence. Few expected to reach old age or to experience any of the concerns, rewards, or dilemmas connected with it. While people typically see old age in negative terms, as a period of decline, deterioration, and loss, our respondents often experienced it in more positive terms. Old age became something not to bemoaned, dreaded and denied, but to be embraced and celebrated. The oldest respondent in the study, a sixty four year old man who had been living with HIV for 10 years commented: “I must be blessed by somebody who is watching over me. It blows me away sometimes. I’ll be 64 this year!”

Age, for many of the older respondents represented a milestone - a victory over HIV and over all the treatment failures, side-effects, searches for new treatments, frustrations, disappointments and losses they have had to endure. One respondent declared:

*I thought I was going to be dead in two years. I thought it was going to be my last hoorah. I was ready for it. But here I am. A little pale, a little thinner. But I’m not sick. I just turned 48. It was a birthday I never thought I’d see.*

The sense of triumph was punctuated by the experience of having seen many of their HIV+ friends and acquaintances die over the years. To have lived with HIV for so long, when so many others had died, made old age an achievement. A 53-year old male who had been living with HIV for 15 years commented:

*When I look at the length of time that I’ve survived, there’s a lot of people who were diagnosed around the time that I was and haven’t survived. I’m thankful.*

## **AGING AS LESS FRIGHTENING THAN EXPECTED**

Relatedly, getting older and old age were not feared in the way they often are among those who are not living with a serious health condition. A consequence of an HIV diagnosis is that it forces people to face their mortality on both an emotional and practical level. Among many of our respondents, fears had been confronted, lingering personal issues had received attention, wills had been prepared and, in

some cases, funerals had been pre-arranged. For those who had done this preparatory work, it had felt strangely “out of sync” to have confronted death at such an early stage in their lives. We normally do not expect to have to think about death while we are still young and may resent having to do so. However, the payoff, as many discovered, was that at least some of this work now lay behind them. They felt that they had in large measure, if not totally, come to grips with the idea of dying and had made their peace with it in a way that made the process of aging less frightening. In this sense, their experience with HIV had prepared them for the experience of aging. A 45-year old man explained:

*I've learned to live with this disease and I know eventually that I'm going to die. Sooner or later down the road, unless of course they come up with a miracle cure...I know it's going to happen someday. When it happens, it happens. I'm ready. I'm prepared. I'm not scared to die. I've come to terms with this disease.*

## **AGING AS LESS OF AN ADJUSTMENT**

Another way in which HIV prepared many of the respondents for the experience of aging concerns the lifestyle changes it had forced them to make. Most respondents described how, in the aftermath of their diagnoses, they made greater efforts to adopt stable and healthy lifestyles, to curb or eliminate their use of cigarettes, alcohol or drugs (legal and illegal), to slow down, eat properly, take vitamin supplements, exercise regularly, get plenty of sleep, seek medical care and comply with treatment regimes, or deal with stress. Though they might not have been entirely successful in their efforts or had not completely reached all of the goals they may have set for themselves, many had made significant changes in their lives and had adopted routines and patterns that better prepared them for the lifestyle changes and slowing down that advancing age often necessitates. The prospect of getting older did not have the implications that it had for those who have had the luxury of living their lives with none of the constraints that disease, disability or ill health imposes. In terms of lifestyle, many respondents felt relatively prepared for old age. They were not expecting the disjuncture or break with usual activities or routines that it might otherwise have been.

## **PROBLEMS OF AGING AS A DISTRACTION**

As mentioned previously, many respondents were experiencing health problems such as weight gain, high cholesterol levels, high blood pressure, heart disease, diabetes, osteoporosis, arthritis and, for women, menopause. While in some cases respondents recognized that these problems might be related to their HIV treatment, in other cases they connected them with the aging process. Though they did not welcome having a whole new set of health issues to deal with, some respondents saw an “up-side” to them in that sense that they provided a distraction - something other than HIV/AIDS to think about for a change. This is not to suggest that individuals ever “forgot” that they were HIV-positive (although some respondents did talk of feeling as though they sometimes *almost* reached this point). Nor is it to suggest that worries about HIV/AIDS ever receded totally. However, to be worried about osteoporosis or arthritis, particularly if a person’s symptoms and/or management requirements are more immediate and demanding, is to be preoccupied with something other than HIV, even if only momentarily. After having lived with HIV for many years, new health worries offered respite and relief.

## **AGING AS NORMALIZING**

Moreover, the health problems often connected with aging are worries that respondents share with many others at the same stage of life who are *not* HIV-positive. They are “normal” problems to have. People living with HIV are often used to being seen as, and feeling, different from HIV-negative others. They feel “set apart” in a multitude of ways. Among them are the ways in which the trajectories of their lives are disrupted, so that they cannot count on experiencing the same sequence of age-related life events as others. Others can live their lives based on the assumption that they will get older and face the adjustment and health problems age may bring; PHAs often do not. To reach a point, then, where they were confronting the problems of aging in ways similar to those around them, made some respondents feel as if they were back “on track.” They saw these problems as symbolic of “normalcy,” signalling a re-alignment of trajectories. In this sense, they experienced them positively. As one respondent – a 56 year old male – put it: “Triglycerides, weight problems, smoking. They’re nice worries to have.”

While being HIV+ gave aging a more positive meaning for many respondents, it also presented unique challenges. In the following discussion, we identify the more significant among them.

## **ILLNESS FATIGUE**

Though most respondents took pride in having lived with, and managed, their HIV for many years, most were also clear about how much work this involved. There were regular visits to a broad range of health care providers, visits that often needed to be undertaken using public transit and that involved negotiating numerous transfers under weather conditions that were not always favourable. There was the difficult task of taking medications. Some pills needed to be taken early in the day; others were taken late in the day. Some were taken with food; others were taken without. Some required refrigeration; others did not. This had implications for how respondents arranged their days, particularly time away from home. There was work around dealing with the side-effects of medications, some of which were predictable; some of which were not. Routine tasks that most people perform effortlessly and without thought - meal planning and preparation, housekeeping, personal care - all required greater time and energy when respondents were not feeling well. So too did all of the additional activities that became important for them to incorporate into their routine, such as exercise or stress management strategies. Given these kinds of demands, even the task of clearing enough space in the day to rest felt like hard work.

Much of this work needed to be done in the context of worries about income and finances. Despite the assistance programs and supports in place, for most respondents providing for even their most basic needs was a struggle. A 54-year old male respondent contrasted his lifestyle with that of his sister, who had just completed a \$20,000 renovation in her kitchen:

*I'm tired of going to food banks. I'm tired of seeking out help from the Hamilton AIDS Network. If it isn't on the drug plan, I cannot get that drug. Even though I need that drug, I can't take that drug because I can't pay for it. I don't have the things that I want to have that I know I might otherwise have been able to afford. I really haven't had a proper*

*vacation in over twelve years. I don't go to restaurants. I seldom go out for a beer with my friends. I haven't been to a movie in years. I buy no-name shampoo and stuff. It's the not having. I'm the poor person in my family.*

The struggle to survive was reflected as well in our experience of tracking individuals to arrange interviews. In a longitudinal study of this sort where we were going back to respondents for a series of interviews, it was possible for us to see how quickly circumstances could change. There were a few respondents who, eight months after our initial interviews, could not be located. Several more of them were living at different addresses, forced to move, in some cases, because of the inadequacy of previous housing. As the stories of their lives unfolded in the interviews it became increasingly clear just how much energy they put into simply making ends meet.

On an emotional level, there was work of another sort. There were the kinds of issues that are discussed more fully in other sections of this report: the more-or-less constant dilemma of whom to tell or not tell, the stigmatizing aspects of HIV/AIDS, dealing with medications and physicians, the pressures to adopt the role of the “good PHA” with all of the additional demands – like community or service work – that this may entail, and dealing with the constant uncertainty about what the future may hold. HIV is a disease of ups and downs. There are periods of health and periods of crisis. Respondents never know whether their next infection will be their last. There was a constant framing and re-framing of where they were in their lives. This forced many of them to live their lives intensely, as if every day could be their last. They took little for granted. They described their lives as being lived day-to-day and moment-to-moment. Time was experienced differently, more protractedly. This, though subtle, seemed to require the most work of all. One respondent, a 60-year old man, admitted:

*Six months is a very long time. With this HIV, things can change so much. My life has been nothing but constant changes for 20 years. Waiting to die and yet living and experiencing every damn thing that happens along the way. It is hard to manage it all. It wears you down.*

Most respondents were highly motivated to do this work. Many admitted, however, that staying positive and keeping their motivation up took a lot of effort. They conceded that there were moments when they simply got tired. As a 50-year old male respondent expressed it: “I’m tired. Keeping on top of it all takes its toll.” A sense of fatigue sets in. The term ‘illness fatigue’ is perhaps inadequate since it suggests a limited view of all that is involved in living with a chronic condition. We use it, however, to try to capture the various, multi-layered and inter-related facets of the experience, including its medical, practical, financial, interpersonal, emotional, and existential dimensions. While others may look forward to the later stages of their lives as less demanding and more relaxing - a stage of life to enjoy - our respondents were facing the prospect of living out their final years with their stores of physical and emotional energy sorely depleted.

## **CONFUSING SYMPTOMS**

Another concern has to do with the physical changes, and new symptoms and health concerns that getting older may bring. Earlier we made the point that these new health concerns sometimes brought a strange kind of relief from having to worry about HIV. However, they also raised troubling questions about what precisely was happening. Were changes such as weight gain/loss, tiredness, memory loss, slower reflexes, and changes in body shape a normal part of aging or did they signal a problem? Were they symptoms to be alarmed about and seek treatment for or were they simply to be accepted? Previous research shows that perplexing questions about how to interpret symptoms and body changes is a preoccupation for many PHAs, whatever their age. “Is it HIV or is it something else?” can be an ever-present question. However, aging, which is in large part about changes, adds to these preoccupations.

Respondents also had questions about how the aging process was going to be affected by their HIV+ status. Could they expect to experience the changes and health problems of aging in the same way? Conversely, what effect would getting older have on the virus? These were questions for which even their health care providers had few answers, adding more uncertainty to lives already characterized by a good deal of uncertainty.

## PAST REGRETS

A third way in which HIV complicated aging has to do with the fact that many respondents had lived longer than they expected and had made decisions they looked back on with regret. The context for this decision-making was explained well by one respondent when he said:

*HIV is something that forces you to live your life differently. Your priorities change. You start to take chances. If there's something you want to do, you do it. You may not get the chance ever again.*

Another respondent, a 45-year old former injection drug user, responded to his initial diagnosis by escalating his drug use:

*[After the diagnosis], I was in shock, like for three months. I started using drugs heavier. I started drinking because I didn't give a shit. I was dying. I thought I was dying. Who knew? A month, Two months. Three months. I didn't care.*

Among the regrets that respondents discussed were decisions to leave the working world, spend savings or to stop putting money aside. This meant that the nest egg that many individuals count on to live out their lives in a particular way was not there for most respondents. They found themselves experiencing aging without the financial resources they otherwise might have had.

In other cases decisions had been made about living arrangements. Some respondents had moved from one community to another, both to get away from situations and influences they felt stood in the way of lifestyle changes they felt they needed to make, or to access family support. In one instance, a husband and father of young children left his family, not wanting them to bear the burden of what he assumed would be a quick and unpleasant death. Others had pulled away from family and friends and centred their lives more around other PHAs and the PHA community.

Most of these decisions were made in the context of assumptions about not having much time left. Yet some of our respondents found themselves, many years after their initial diagnosis, still around and having to live with the reality of earlier decisions. Among these harsh realities cited by our respondents were decimated finances, broken ties with people that were once important to them, isolation or perhaps narrower social circles made up mostly of other PHAs, and long, empty days. Almost all of the respondents who had lived with HIV for some time had “if only I had known” stories to tell. Reflecting on a work-related decision, one respondent mused:

*You're doing well. You want your life back. You want to be at work, but that's never going to happen. You can't go back.*

## **FUTURE WORRIES**

Besides regrets about the past, many respondents simply did not know what sort of future to plan for or even how far into the future to look. A 63-year old woman described how since her diagnosis six years previously, she lived her life in six-month intervals, adjusting her planning time-line to one year only after several years of relatively stable health.

*Six months was my baseline. My vision. I took six months at a time. Now I don't look at it, like in those small packages of time anymore. Now I can go a year or even longer. But you know, the fact that I can go anytime is always in the back of my mind. Like you think about it everyday.*

This uncertainty, in combination with the experience of having made decisions that in hindsight were seen as regrettable, invested the task of planning with significant ambiguity. As a 47-year old female respondent reasoned:

*You don't know what to plan for. I don't know if I should be working an extra job or trying to put money into an RRSP, or starting some sort of business so that when I get to*

*retirement there is something there for me. Am I going to get to retirement? I don't know.*

Similarly, a 52 year-old man, considering the possibility of looking for an apartment with a younger boyfriend, wondered about the wisdom of such a move:

*What if something happened to me? We get a fourteen hundred dollar a month apartment, let's say. He couldn't afford to pay for that himself. He'd have to move in with his parents. That's what is on my mind.*

This was the experience of respondents during times when they felt they had at least some measure of control over their decisions and their lives. There were other times when they felt they were living life more reactively than pro-actively. At these moments, the very notion of *planning* for the future felt foreign. The issue was less about planning for the future and more about not knowing what sort of future to anticipate or envision.

## **CONCLUSION**

A diagnosis of HIV often disrupts life in a way that makes aging seem like an unlikely prospect. Yet, with advances in treatment options, more and more people with HIV are facing the reality of getting older. This section has explored what that experience is like.

A central theme that emerged from the data is that HIV can give aging alternative, even positive, meanings. In a culture where youth is valued and where aging is often associated with decline and death, HIV can offer reasons to feel good about getting older. Age can become a symbol of triumph and achievement rather than of decline and loss. Moreover, PHAs, by virtue of their experience with HIV, may be better prepared for getting older, both mentally and in terms of lifestyle adjustments.

The more positive aspects of aging with HIV, however, need to be juxtaposed against the unique challenges that PHAs confront as they age. The management of HIV over a prolonged period of time may result in a sense of fatigue. People simply tire of the work involved in caring for themselves and managing their lives. As bodily changes occur and other health problems arise, their management strategies need to

be reconsidered. There are new worries about how to interpret what is happening to one's body and what steps should be taken. Aging may also force a reframing of the kinds of trajectories PHAs imagine for themselves. A diagnosis of HIV leads many people to live life in the short-term. As they find themselves getting older, they may begin to revise their expectations and re-think the time frames they apply to their lives. This process often entails facing regrets about past decisions, but also greater ambiguity and uncertainty about just how far forward to look.

The experience of PHAs clearly demonstrates the subjective and illness-specific dimensions of aging. Aging is more than a linear or chronological progression through the life cycle. It is a lived experience with individuals bringing different meanings and concerns to it. What our study suggests is that when aging is experienced in the context of a diagnosis like HIV, it is important to examine precisely how HIV figures into the experience. The process of aging - the rewards it brings and the issues it raises - cannot be separated from the realities that HIV brings to people's lives.

## 4. MEDICATIONS AND HIV

Over the course of the HIV/AIDS epidemic the level of optimism about the potential of medications has fluctuated. The introduction of the drug AZT in late 1980s gave hope that it might be possible to treat HIV. However, after several years of use, it became evident that AZT alone was not as effective as anticipated (Ariss, 1996). In 1996, at the International AIDS conference in Vancouver, research was presented showing encouraging results from clinical trials of protease inhibitors, a new type of medication that when used in combination with other drugs helped delay the progression of HIV/AIDS. While these new treatments – commonly referred to as highly active antiretroviral therapy or HAART - have helped to improve the health of many people with HIV/AIDS, their overall impact on their lives and well-being, particularly with side effects, has been questioned.

In this section we examine the subjective meanings of AIDS medications for people with HIV/AIDS and the implications for treatment and care decisions. The possibility that medications can effectively treat HIV has been a particularly salient concern for those infected. With this gradual advancement in the development of treatments, medications have come to play an increasing role in the management of HIV infection. New AIDS medications have brought about health benefits, but they have also created health problems, and none has lived up to its initially anticipated potential.

The symbolic value of AIDS medications for the people with HIV/AIDS in our study was both diverse and strongly felt. Many respondents recognized and struggled with the paradoxical meanings of medications as both a potential means of survival and a source of sickness and death. AIDS medications represented the possibility of long term survival, particularly among those who were newly diagnosed. At the same time, respondents also understood medications as potentially toxic and dangerous. What emerged from our interviews were two sets of meanings about medications, positive and negative.

### THE POSITIVE SIDE OF MEDICATIONS

There was a general belief among respondents that the medications currently available were effective in treating HIV/AIDS. This belief was an important factor in

decisions about continuing to use treatments. As in the case of this respondent, even in the face of doubts or side effects, medications are perceived to be a lifeline:

*It has been seven years that I have been taking medication.  
Because I know one thing, I don't want to die. I know the  
medications will help me live longer but it is paying the price.  
It is being nauseated and sick everyday from the medication.  
Is it worth it or not? I think about that sometimes. I know  
what is probably keeping me alive – the medications.*

This sentiment was also expressed by respondents who had not yet started taking medications – “once I get sick I can take medicine for HIV. There's still time for a cure” – and respondents who had decided to stop taking medications:

*I took them for maybe two or three weeks but they didn't  
agree with me. I knew right away. So I just said, 'No more.'  
And I felt fine for the longest time. In between I didn't feel so  
great, little things, but by not taking those I did myself a  
great favour because all the new drugs could take effect much  
better.*

Evaluating the benefits of medications was done using a range of measures. Most respondents closely monitored their t-cell and viral load counts and used this information along with advice from their physicians to make decisions about medications. In addition to medical markers and professional expertise, respondents also relied on their own knowledge and expertise. In one case, despite the advice of his physician to try new medications, one respondent insisted on remaining on AZT monotherapy, an approach that had, in his estimation, worked fine for over ten years:

*My doctor has been trying to convince me that there's  
no possible way that AZT is doing you any good anymore. I  
keep saying to him I've had no opportunistic infections. I  
don't have any reason to say that the AZT is not working.  
I'll just get to the point where I realize because of my body  
that these two little pills or these six little pills every*

*twenty-four hours are not doing anything. It's not a false sense of security that I have in these little pills. It is the concept that if something is holding as well as it has I don't want to mess around with it.*

While there was some uncertainty about the clinical effects of medications, most respondents felt that there would be new breakthroughs in the treatment of HIV/AIDS in the near future. This belief reflected a general sense of promise and guarded optimism about the overall benefits of AIDS medications. Medications came to symbolize for many respondents a means by which to overcome illness when it arose. They had witnessed, or heard stories about people who had recovered dramatically from illness as a result of medications. The belief that many respondents had in the effectiveness of medications gave them a sense of hope and optimism about their future.

There are meanings associated with AIDS medications other than their promise as effective treatment. The sentiment that you 'can't live without them' was also seen in the association that respondents made between using medications and doing something positive in dealing with their HIV infection and attending to their health. Being on medications meant taking positive steps to care for themselves. Often this sentiment was expressed in relation to keeping on top of a daily routine, as in the case of this respondent:

*I'm going to take care of myself. ... I have to eat healthy, I have to avoid stressful situations by all means, and I have to take my medications. Then I have to see a doctor, which I plan to do right now. I'm doing all the things, except seeing a doctor and getting lab tests.*

Or, in discussions of health status:

*It's pretty good. I take my medications everyday. I'm not morbid about it. It's not always on my mind. I remember to take my medications. It is always kind of in the background. And you know, I'm watching the calendar when my next doctor's appointment is coming up.*

Medication use was not only seen as a key component of taking an active interest in respondent's own health. Several also saw their involvement in clinical trials (and their involvement in this research project) as a way of making a positive contribution to the health of people with HIV/AIDS in general.

*I put my name down and said, 'hey, if you want me to go on clinical trials or some special, little doo-doo, sure, I'll do it.' And I did, and I felt better because now I'm giving something back to society, like, doing this now. And this is the third time I've done something like this.*

Underlying the feelings that respondents expressed about the significance of using medications as a component of self care was the sense of security and reassurance that they provided. On an individual basis taking medications was reassurance that respondents were doing the right thing and that would translate into improved or sustained health. Using medications and being involved in clinical trials contributed the feeling of security that comes from being part of a broader struggle to make the situation better for all people with HIV/AIDS.

Medications seen to be beneficial at an individual and collective level; they were symbols of hope and promise for the future. This was the prevailing view of the role that treatments should play in the management of HIV/AIDS. It is a view that is supported and reinforced by physicians, pharmaceutical corporations, the media and other authorities. This point of view was reflected in the meanings that people with HIV/AIDS associated with AIDS medications. However, the promise or necessity of medications was rarely expressed without some reservation, scepticism, or doubt. In discussions about the positive symbolism of medications was a recognition that there are limitations to biomedical treatments: they don't always work, often involve serious side effects, and can cause serious illness.

## **THE NEGATIVE SIDE OF MEDICATIONS**

As much as respondents spoke about positive associations, there was a negative side to the use of medications. The sentiment 'you can't live with medications' was strongly felt by many respondents, particularly those who had experienced difficulties in using biomedical treatments. The negative and damaging effects of medications were often met with a combination of anger, fear, and resentment.

A fear that many respondents expressed was that their medications would do more harm than good. The toxicity of medications was a central concern in this regard. As in this case, many respondents associated harm with the side effects of medications:

*The side effects really didn't go away. They weren't as severe as what they were with the other pills. But they really never went away and again, I just never felt good. I knew what was making me feel shitty, it was these handful of pills that I was taking. Because they're poison; they're poison. That's what was making me feel nauseated; it was making me depressed.*

Even if someone had not experienced side effects directly, he or she knew someone or had heard of someone who had, and was aware of the potential complications. There was a considerable amount of fear and anger expressed with side effects and their impact on the lives of people with HIV/AIDS.:

*I don't believe that HIV medication is the answer. It will keep your counts up, keep your immune system good but down the road you will not be able to walk, you'll have a third hump growing out of your back, half your guts will be so rotten that they will have to rip them out. I feel amazingly better than I did when I was on the drugs. When I am on the drugs I am pulled down. I am just sick. I go on the things and it's like sick. I'm just sick all the time. It's really a quality of life decision.*

Dealing with side effects, or the possibility of side effects, was a central theme in discussions about the use of medications. Respondents experiencing side effects talked about the dilemma of whether to continue taking medications, given the severity of the illnesses that they were experiencing. Often respondents with side effects felt better when they were not taking medications, as in the case of this respondent:

*Whether or not to keep taking the medication? A lot of the times I felt like stopping the medications because I was feeling*

*good before I was taking the pills. Ever since I have been taking the pills, I have been sick.*

At the same time, respondents recognized that not using medications because of side effects might make it harder to keep their HIV infection under control.

Concerns about toxicity influenced decisions about when to start and stop medications. There were respondents who were cautious about using medications, in some cases despite low T-cell and high viral counts, because of the severity of side effects. For several respondents illness from medications, as in the case of this respondent, lead to them rejecting biomedical treatments altogether:

*Leave me alone because I'm happy where I am. If I get sick we'll deal with the pain and just let me go. I don't want to take drugs anymore. Not until they find something or tell me that I'm not going to have these major toxicity problems or neuropathy, or I'm not going to be puking my guts out all the time. No, I don't want it anymore. I've made up my mind now.*

Toxicity, side effects, and the long term effects of medications were mentioned by respondents who were asymptomatic or thought of themselves as 'long term non-progressors' as a key factor in their struggle with the decision to start treatments after the onset of illness or when their T-cell count and viral load changed to point which suggested that medications might be an option.

*My health is good. Let's worry about it later. And that's basically the end of it. I'll worry about it when I have to. I've just been keeping a good check and keeping a good eye on it, and as time has gone by, all the recommendations as to when you start therapies, when you do n't start therapies, interrupted therapies and all that stuff, all these are new ideas and new concepts.*

Another common sentiment regarding medications was that they were an intrusion into the lives of respondents. This sense of intrusion took several forms. First, the

pills themselves became a sign of their HIV status both for themselves and those around them. This reminder, and source of potential disclosure, was a burden, particularly when combined with the chore of having to take so many pills on strict regimen over a long period of time:

*I used to be totally optimistic. And then I became a big pessimist. [HIV] is always there. That's one thing I'll say. When I didn't take any medications there were days when I didn't think about it. Now it's constantly there because the pills are constantly in front of me. It's a constant reminder. Popping these pills everyday, it's like, wow. When I wasn't taking any pills, there were days when I didn't think about it, weeks when I didn't think about it. Now I think about it everyday because I'm taking pills everyday.*

The idea of intrusion extended to what the pills and medications represented for people. They were not only a reminder of HIV, but a reminder of failure or decline in health. Not responding to medications was interpreted as meaning that severe illness and death were not far away, as expressed by this respondent:

*I'm just afraid right now because the other medications were not working for me and this stuff isn't also working. I starting to worry again for the last couple months because I'm thinking, "I don't think any more medications are going to work for me now." Maybe it's getting close to the end for me.*

The emotional health of many respondents suffered because they had to manage the negative side of using medications.

To take the view that you can't live with medications is to challenge the prevailing approach to treating HIV. This tension was apparent when respondents expressed frustration at feeling mistreated by the medical system as a result of their approach to using medications.

*I was put on a triple cocktail. We're talking about almost thirty pills a day. I don't eat three meals a day. I didn't*

*work. I tried to tell the doctors, "Look, this is not for me. Please, this too much. I'm getting sick." I went down to a hundred and six pounds. We're talking two years now into the disease.*

In such situations, medications came to represent an injustice or disservice. Several respondents reacted in this way when involved in clinical trials.

*I'm known as human guinea pig down there with the studies and that. I told them, 'If you got any medication that's new and if I fit the criteria, put me in there.' Yeab, getting sick all the time, throwing up, not being able to eat, or having problems getting out of bed, after a while, you get used to it ... . Because you never know. The next pill that they give me may just cure or kill.*

Regardless of whether it was about being involved in clinical trials, or feeling as if they were being prescribed medications as a matter of course, or being controlled by a medication regimen, used the term 'guinea pig' to express their frustration at feeling as if their needs and interests were subservient to the priorities of the medical system.

## **CONCLUSION**

As studies of people with HIV/AIDS have shown, medications play a central role in the lives of those infected (Adam & Sears, 1996; Adam, Maticka-Tyndale, & Cohen, 2001; Making Care Visible Working Group, 2002). Akin to the work of the Making Care Visible Working Group (2002), who stress of social character of treatment decisions, we have in this section tried to illustrate the symbolic value of medications for people with HIV/AIDS and the impact of this symbolism on health and health care decisions. Medications had a wide range of meanings for respondents: hope; a future; health; experimentation; poison; toxicity; death; a life line; sickness; illness; infection; and intrusion, to name only a few. Such associations were often combined together in complex ways and were not fixed but evolved in relation to personal experience, social relations, and social circumstances.

The meanings of medication for respondents were rarely straightforward. For instance, people with HIV/AIDS recognized and struggled with an understanding of medications as both signifying the possibility of survival and the possibility of sickness and death. In some cases, meanings were contentious, both in relation to accepted medical guidelines for treatment and care and in relation to an individual's own sense of approaching treatment and care decisions. The meaning of medications helps to provide a frame of reference for health and health care decisions, such as when to start using or stop using treatments. Respondents who see medications as either toxic or ineffective often delay using them for fear of health risks, side effects, and/or resistance to specific treatments. The symbolism of medications also played an important role for people with HIV/AIDS when considering whether to prioritize quality of life over longevity when making health and health care decisions.

In most decisions regarding medications there are both advantages and disadvantages and people with HIV/AIDS must weigh the costs and benefits. This weighing involves not just clinical considerations, but moral and ethical considerations as well. Questions regarding quality life versus longevity and when to start or stop medications were considered in relation to respondents' sense of identity, their hopes and fears, and what is valued in their lives.

## **5. PHYSICIAN AUTHORITY AND HIV**

With the diagnosis of a long-term illness comes the almost inevitable beginning of a relationship with the health care system. People living with chronic illness often have long and varied relationships with health care providers. They have been “catapulted” into these relationships without choosing them and usually with little preparation. They may need the service of health care professionals intensely, continuously, occasionally, or not at all. They quickly find themselves immersed in an entirely new culture characterized by new information about their disease, a new language, power dynamics, and differing attitudes and values. While seeking simply to do all that they can to stay healthy, people with HIV/AIDS, as with any illness, soon discover that interacting with their health care providers can be a great support, as well as a great challenge.

Throughout the HIV/AIDS epidemic, those infected have had to learn how to work effectively with health care providers. There is a lot of information available on relationships between health care providers and people with chronic illnesses. There is much less information specifically about people with HIV and their health care providers. Respondents in our interviews often spoke about these relationships. In their stories, they included nurses, social workers, physicians, practitioners of complementary and alternative medicine, and others. We heard the most from our respondents about relationships with physicians, and this is the theme we will focus on here.

Although most respondents in our study were receiving care from physicians, several had chosen not to. Both those who were in care and those who were not contributed perspectives that provide important understanding of how people with HIV navigate these relationships.

### **PHYSICIANS AND LEGAL AUTHORITY**

On the one hand, our respondents spoke about the role of their physicians as that of an ally, a helper, someone they could talk to and depend on, an advocate, someone they needed as part of their strategy for staying healthy. On the other hand, some were afraid that their physician could undermine them in some way. In some cases, people believed that physicians were obligated to report certain information to the

government, especially if they were doing anything potentially illegal. Respondents recognized that physicians were gatekeepers to a variety of services such as disability benefits, subsidized housing, prescription medications and access to marijuana. This legal authority (sometime called statutory authority) often created a difficult dynamic between the physician and the patient, sometimes to the point that the respondent decided not to be involved in medical care. We interviewed an HIV positive woman from Africa who was seeking refugee status in Canada.

*I have not gone to any clinic. Why? Because I'm afraid. I know if I go to a clinic or something, they'll probably give my name to the government and I don't know what is going to happen to me. I don't know if they'll put me in some kind of program. I'm sitting on the fence really. I need their help really. I really do.*

In this woman's case, the fear of betrayal from someone who is supposed to be an ally created overwhelming internal conflict. Her fear was a barrier to receiving medical care. She chose to accept the risk to her health rather than the risk of losing a safe country to live in. Other people whom we interviewed had actual experiences of betrayal. One woman said,

*I didn't see [my family doctor] because he was spreading my information to my family members. So, I had to search for a family doctor.*

Some people found their physicians worked with them as advocates in obtaining needed services and resources, while others felt their physicians were obstructing this access. The physician's legal authority in these situations could function at once as a positive experience for one person seeking service, while for another it created fear, uncertainty and sometimes disappointment.

## PHYSICIANS AND EXPERT AUTHORITY

The priority of access to unbiased information about health, disease and treatments has been a remarkable social response to the HIV epidemic. Few medical problems have pushed the access to information agenda as radically as HIV/AIDS. Physicians are one source of health information. Their expertise can be accessed and used in a variety of ways. Our respondents spoke at length about accessing appropriate information, and the role of physician expertise in their health care strategies.

*In the beginning, I didn't have a very good doctor. He wasn't very well informed. It didn't take me long to say, "It's time to find a new doctor." I found a new doctor and he was excellent. [I know when they are informed or not] Because I keep up pretty good too. If I ask a question and they don't know what I am talking about, that's a big clue right there. "Well, you should know just as much as I know, that's your job. You're my physician"*

Many respondents described how they maintain a current knowledge base about HIV, and about their own health status. For some there was a turning point when they realized that they needed to take control of their health information, if not also their health care. This turning point was often the realization that something had been missed or a mistake had been made because the physician was not paying close attention to laboratory results or other information. At other times, people seized control of their medical care or information when everything else in their lives felt out of control. Some kept their files of their own health information, and others insisted on receiving all the information that the physician did.

For those who felt the need for more control over their medical care or medical information, some were able to negotiate this successfully with their physicians, while others were not. One woman who had decided that she would no longer pursue a relationship with a physician said,

*I've had doctors who say, "Well, you have to do this, this and this." And if you don't, then you feel like you're disappointing them. And it's like, I'm not there to either give*

*praise to them or to disappoint them. I'm there to ask their opinion because they are an expert, and then make my decision. It's not about pleasing them.*

This woman expected to have final authority over her treatment and health decisions. She saw the physician as a valued partner, a collaborator, in her health care. She expected to receive information and advice, but resents that they seem to expect her to accept and follow it. She felt her own expertise, and her need to practice self-care, were not valued by her physicians. This contributed to her decision to discontinue medical care. Another man said,

*I can't even begin to describe how bad I suffer taking these medications. When I have doctors saying, "Oh, no, you can't be going through that. We've never heard of that". Well, I'm living it. They just don't listen to you. I thought, "Well, to hell with this. We're going to play this game my way now." That's what it is, it's a big game with these guys. If you don't follow their protocols, it's like pulling the horn out of a charging rhinoceros to get anything done.*

We heard this kind of comment frequently in our interviews. This power struggle occurred most commonly when decisions about antiretrovirals were being made. There was a sense that, as patients, their perspectives, priorities and knowledge were not taken seriously by the physician. The physician seemed firmly attached to a certain way of thinking about his or her medical practice, a certain 'standard of care', and there was resistance to compromise or to adapt this practice to the unique predicament of the patient.

*The only thing that she was concerned about was reading my viral load. She's living by the numbers. You're living by the numbers, and yet I'm trying not to live by this but you're making me feel fear and feel like I'm falling apart because the numbers say I am. But I don't feel like I'm falling apart. I'm doing all these things positive like exercising, I eat so well, I pay so much attention to all this stuff.*

There were also respondents who valued having control over their health care decisions, and were able to work with a physician in a collaborative way, as in a partnership. One woman told us,

*The woman that I have as a doctor seems to be very unusual in that she will ask me what I want to do. She will give me the options and then she truly does let me choose.*

And explaining how he worked in partnership, a male respondent said,

*I met with her and we had a really good meeting. I wanted to identify the threshold where I should start drugs because I hadn't started drugs yet at all. Then we talked about that within the six months, if I did start, what would be the choices, what was I looking for, and what was important in my choices around drugs. So, I made those choices. What I was looking for with physicians usually is a doctor who is going to interact with me as opposed to just telling me what to do.*

For these people, the information, knowledge and experience that their physician offers, and that they themselves have, all come together in a satisfactory balance. Pivotal in these positive experiences seems to be a mutual appreciation of what each person brings to the decision-making table. Power and authority are balanced, and the physician genuinely seems to value the priorities and perspectives of the person receiving care. Power struggles over health decisions don't occur here, as neither party seems threatened by what the other expects.

Finally, we heard from some people who preferred not to be involved in understanding or weighing options. They assigned the responsibility to the physician to be the primary decision maker. They preferred to delegate control over this part of their lives. One man told us,

*I let the doctors do what they are supposed to do. If they throw up a flag, saying, "You got a lymph node infection", I would be like, "Okay. How do we treat it?" They'll say,*

*"Here's an antibiotic." I'll take it faithfully. If it's the only choice I got, I'll deal with it. I'll say, "OK, I trust that my doctor knows what they're doing because they went to school for it. I didn't." I got to believe somebody.*

Allowing someone else to manage these details can offer a sense of freedom, or an ability to focus on other issues. It may also reflect a degree of trust in the medical profession. For some, it appears that following a physician's advice is one way to show appreciation for what the physician has done, accepting treatment advice as a 'payback' for his or her efforts:

*I liked [being in the studies]. Oh yeah, for sure. I knew some of these drugs were approved in the States and they weren't approved here. I thought, "I'll do whatever I can to get those drugs approved in this country for other people to go and get them." He was spending money out of his own pocket to get these drugs into here for us to take them. I thought it was a great thing for him to do. I had no problem any time that he said, "I got a new trial. Do you want to start?" I said, "Sure enough, sign me up." Every time.*

## **PHYSICIANS AND MORAL AUTHORITY**

Another kind of authority that some people experience from their physicians is moral authority. People's HIV diagnosis, their sexuality, their beliefs about medications, or their behaviours may receive either approval or disapproval from physicians. We heard how a physician could make one feel like a good person, or a bad person. One man expected to be treated poorly because of his need for morphine, but to his surprise his physician conveyed approval.

*I've been going to see her for over a year now. She knew that I was in a federal halfway house when I first went there. I didn't feel uncomfortable at all. I was being prescribed morphine for pain at the time. She didn't look at me as a drug addict or talk down to me. There was a couple of times*

*when I was in between doctors and I couldn't get anyone to fill out my prescription for morphine and she did it for me. She really talked to me about getting off the morphine. She's pretty instrumental, I think, in getting me off the morphine and into the methadone program.*

In contrast, another man said,

*I wasn't sleeping for a while there, and I asked him if I could get a couple of days worth of sleep medication or a week's worth, just to get back in the routine of sleeping, and he kind of made me feel like I was drug-seeking. He kinda made me feel kinda awkward.*

When asked whether he would be comfortable asking his doctor for information about marijuana, one man said,

*I could, but I'm not sure she would know or if she would tell me if she didn't want me to know. She doesn't really believe in smoking pot. She's one of those.*

Physicians have the power to confer upon their patients a sense of moral status as these interactions and comments attest. The statements above reveal the ways that people seek the approval of their physicians, and how they sometimes look for clues about whether this approval is forthcoming.

## **CONCLUSION**

In their interactions with patients, physicians' opinions and behaviour can carry considerable weight. Their power takes a variety of forms, and is a force that people with HIV must learn to negotiate. Legal authority, authority of expertise, and moral authority can all work either to the benefit or the detriment of the patient.

Successful treatment relationships seem to take place when the patient and physician are able to negotiate a relationship that is appropriate for both parties. In some cases, this means the patient expects to receive and to accept the advice and service that

the physician feels is most appropriate. In other situations, the expectation of the patient to have authority and control over his or her treatment strategy is honoured by the physician, and a decision-making partnership is established. The appropriate interactional style can change over time, as patients' health change, as they begin new treatments, or as they become more informed about their health care options.

This understanding is important for physicians to integrate into their work. For physicians, knowing the ideas about authority that their patients bring a relationship can help them to provide better care. Physicians may want to consider the kind of collaboration that different patients expect, and address this directly in the course of their work together. It is also important to consider how well they know and accommodate the patient's experience and priorities as a treatment regime is developed. Physicians may benefit also from some reflection upon their own needs within the relationship, and how important it is to them that patients follow the standard of care and practice with which they are familiar.

## 6. RESPONSIBILITY AND HIV

Most people think that health is largely a matter of individual or personal responsibility. This emphasis is reflected in much of the scholarly work on health and illness. For example, treatment adherence has been studied largely in relation to psychological models of individual behaviour (Ajzen, 1991). Psychological models explain adherence to medication as a matter of how people think, how they perceive themselves to be at risk, and how they weigh the relative outcomes of one behaviour over another. In contrast, this section examines the health-related behaviour of people with HIV/AIDS (PHAs) against a backdrop of increasing expectations to take responsibility for their own health, an increasing trend over the last 20 years in Western societies. A weakened social safety net in many Western societies has meant that greater emphasis is placed on self-reliance, self-control and individual responsibility for health (Petersen & Lupton, 1996).

In this section, we address a number of issues related to morality and health that emerged in our study. Some people with HIV/AIDS we interviewed blamed themselves for having HIV. Many also felt the expectation from others, as well as from themselves, to be engaged and compliant patients – ‘good PHAs’ – and to actively contribute to society.

### MORALITY AND HEALTH

HIV has taken on particular moral meanings in our society. As discussed earlier in the report, HIV/AIDS has been highly stigmatized. Herek and Glunt (1988) contended that discriminatory responses to HIV were epidemic in North America, particularly in the United States during the 1980s. Fuelling AIDS-related stigma were the facts that AIDS was at the time a terminal, wasting disease that visibly marked its sufferers; it was acquired through stigmatized activity (anal sex, drug use); and, most important, AIDS affected already stigmatized groups, most notably gay men.

Even in 2004, people with HIV/AIDS are still blamed for their infection: moralistic proscriptions against drug use, homosexuality, the sex trade, and promiscuity abound. People with HIV/AIDS frequently internalize these beliefs and, consequently, blame themselves for their HIV infection. We often heard self-blaming statements from respondents, particularly from those infected through

stigmatized behaviour, such as shared needle use, or through unprotected anal or vaginal sex (with both casual and intimate partners and sometimes in the sex trade). A 33-year-old, heterosexual man with a past history of injection drug use said, ‘Well, being a user, getting this virus, a loser life got me here.’ For this respondent, his earlier life led to his HIV infection and poignantly he could not forgive himself. Another, a gay man, aged 40, believed that his naivety caused his infection:

*I could have prevented it. I think I blame myself. I should have known better, but I was really young, trusting, and in love.*

## **RESPONSIBILITY AND THE DUTY TO BE GOOD**

For many people with HIV/AIDS, contending with the moral stigma of HIV is both a long-term struggle and a central influence on how they approach their health. In this study, for example, participants first blamed themselves, then wanted very much to “do the right thing” or “be good.” Some accomplished this by abstaining from sex or injection drug use, feeling a responsibility to protect others from getting infected and themselves from worse HIV disease:

*I can do things right now. I can take responsibility and not give this to anyone else and not make myself sick.*

Others intensively managed their disease, seeking to control it by following what they viewed as prescribed ways of living with HIV. For example, many volunteered for research about HIV, searched the Web, accessed libraries (including scientific journal articles), and asked their doctors for additional information. Some monitored their T-cell and viral-load counts (measures of relative illness), and rigorously followed physicians’ orders. One participant offered a framework for understanding this phenomenon; she referred to it as being a ‘good PHA’ – one who strives to be seen as moral and as accepting personally responsibility for improved health.

*I think a good PHA goes to the doctor regularly, listens to what the doctor says, takes their meds on a regular basis, and does not do unanticipated interruptions, and gets enough sleep, eats properly, and all those sort of pollyanna things*

*that people are supposed to do. I think there are people who work very hard at being that....good PHAs. I would call them 'born again PHAs.'*

The same participant went on to criticize what she perceives as a false sense of security created by approaching one's health in this way:

*I think it's a false sense of security, like when people try and do the good thing of staying on top of their numbers for example. I think it's a false sense of control. I think for some people it helps them feel that they are handling the virus. So I don't say that to people when they start going on about their viral load or they start going on about their CD4 cells because I realize that's very important to them, but my attitude would be that it's a false sense of control. ... I know when I'm getting sick. I don't need to know the difference between I'm getting sick because I've got 50 CD4s or I got 10. Or I'm getting sick because I got 200. I'm still getting sick, and that's the bottom line for me.*

In subsequent interviews with participants, we questioned the pervasiveness of this phenomenon and discovered that many felt the same expectation. Infected through shared needle use, one gay man had been living with HIV for nearly two decades. He took very seriously the work that lay ahead of him: doing all that was possible to maintain his health. He spoke of his past drug use and what he felt was his responsibility to look after both himself and others:

*Q: Some people say that being a good PHA means going to the doctor on a regular basis, watching your diet and nutrition, getting exercise, not smoking, following your numbers really closely. What do you think of that?*

*A: I think we have a responsibility to ourselves to do that. Others won't care about me if I don't do it myself. I was a user. I think I have a chance again in life to do things for*

*others that I never could do for myself. And that is how I see my life ahead – like I said, it's a job for me.*

Another gay man, who had been living with HIV for 15 years, spoke about the hard work involved in managing his own health, in complying with prescribed treatments, and in ensuring that his doctor knew everything about his health maintenance strategies. He also illustrated, however, the ease with which people morally judge those who do not subscribe to the notion of a 'good PHA':

*I'm very compliant. I mean they called me born-again, right? I always do what I'm supposed to do. I know that sometimes the dose doesn't happen or, 'Oh, my God! I forgot to bring them with me. Oh, I just won't take it, some say. You know what? Don't take it at all. Do us all a favour because you're going to be the first one that's going to be crying the blues when you find out that you're resistant. So I'm very compliant. So in that category, yes, I would be considered a good PHA. I will do what I have to do to maintain the best of levels of health that I can. I'll tell them. It's not going to be a guess. I'm not going to lie to them. I tell them everything that I'm doing. [Do you take anything extra?] Yes, I do. I tell them what I'm doing so they're informed. I'm proactive about my health, so that's where I think I'm a good PHA, because I'm not expecting that everybody else will make all the decisions for me.*

A third gay respondent, in his late 30s, said that being a good PHA counterbalances activities that others might find health damaging:

*Yes, I am being the good PHA, but I'm the bad PHA when I drink and abuse my body. In other words, I do what they say I should do as a way to feel less guilt about drinking, doing drugs, whatever. You have to listen to your doctors, after all.*

These last two quotes illustrate the expectations that PHAs can experience to conduct their lives in particular ways. While the media, PHAs physicians and counsellors, and other people with HIV or AIDS may all serve as sources of support, knowledge, and mentoring, they can equally perpetuate the idea that PHAs need to maintain their health by being “good.”

## **GIVING BACK TO SOCIETY**

Respondents in our study frequently mentioned wanting to be seen as doing something meaningful with their lives or actively contributing to society. This took on different forms for different individuals. Some, for example, felt obligated to enrol in clinical trials for new medications; some wanted to do volunteer work. Respondents wanted to enrol in clinical trials despite possible bad side effects:

*They're experimenting every time they try something new. Taking me off meds for a month to try something new. So it's an experiment like trying new pills and seeing what the reaction is. I feel like a human guinea pig – a major human guinea pig. After 14 years of being a guinea pig, I'm tired of it. We were watching the news the other night and there's this new drug that's out that is showing good signs. [My partner and I have already told our HIV specialist] that we want it. As soon as it comes across, we want it. Every time something new comes up, my name is right there. Because you always want to get better.*

By volunteering for clinical trials, other PHAs wanted to give back to society or help others:

*That's why I put my name down and said, 'Hey, if you want me to go on clinical trials, sure, I'll do it. And I did. And I felt better because now I'm giving something back to society.*

Still others, believing that they have been given a second chance to stay alive as a result of antiretroviral drugs, felt strongly about volunteering or returning to paid work as a means of contributing to society:

*I never complain about my health. I do the things that I have to do. I go out and do what I have to do. If there are any appointments, I'll go. I'll try to get out and volunteer and do stuff. I don't stay home.*

## CONCLUSION

Broad social and political shifts in Western societies over the last 20 years have had an impact upon individuals' perceptions and experiences of health. The predominant shift has been to neoliberalism, where governments are less and less responsible for citizens, downloading responsibility for health and health care onto individuals and families. Under neoliberalism, disease and health concerns are privatized. The current mantras in health are self-control, self-reliance, and self-care.

It is against this social backdrop that we understand 'good PHAs,' people who initially blame themselves for their infection by viewing their past actions as immoral or irresponsible and then saw a chance, through managing their health, to make things right. Even those who did not blame themselves know that HIV continues to be stigmatized, and may work to maintain a sense of themselves as moral and responsible. We often heard from people with HIV/AIDS that they wanted to return to work, wanted to be involved in clinical trials, and wanted to be active, contributing citizens. We do not often consider how social and political forces impact these desires. Without setting these health behaviours and issues in their social and political context, we can only describe, not analyse, them. For example, with the arrival of antiretroviral drugs, those in the HIV field assumed that people with HIV/AIDS would feel better and want to return to work (because work provides stability, structure, belonging, contribution to society, and meaning). We rarely consider how moral judgements about people who do not work might significantly affect the ability for people with HIV/AIDS to return to employment.

The findings from our study suggest three principles behind the concept of the good PHA. The first is personal responsibility for health. The second is an intense desire of some people with HIV/AIDS to be seen as moral people. The third is the duty to be good, an expectation that some people with HIV/AIDS feel (from inside or outside themselves) to be active citizens, contributing to society through volunteer and paid work, and involvement in clinical trials. People with HIV/AIDS who do

not subscribe to these three principles risk being regarded – and regarding themselves – as irresponsible and immoral. In western societies, citizens come to accept that it is their duty to be aware of health risks and to follow experts' advice. It is evident from this study that people with HIV/AIDS, to varying degrees, feel it is that it necessary to take personal responsibility for their infection and their health. While this may not be unique to HIV/AIDS, the stigma that continues to surround the epidemic may mean that it is more acutely felt by PHAs than by people with other health problems.

## 7. CONCLUSION

Living with HIV means navigating change. Respondents' personal and social lives change as a result of their initial diagnosis, as a result of starting, changing or stopping antiretroviral medications, as symptoms appear or diminish, and as they become more knowledgeable about and more immersed in the world of HIV treatments and services. Life with HIV not only means dealing with medical realities, it means dealing with the social fallout of HIV. This idea was perhaps most clearly expressed by the respondent who said that one of the results of living with HIV means "experiencing every damn thing that happens along the way."

The focus of our attention in this report has been the *trajectory* of HIV. Coming from the work of sociologists Anselm Strauss and Barney Glaser (1970), the term 'trajectory' has a particular meaning in the social sciences. To speak of an illness trajectory is to refer to more than the biomedical progression of disease, as physicians might do in referring to the natural history of HIV. Many of the changes that PHAs must navigate undeniably result from the biological progression of HIV and the body's response to it. The general course of infection can be highly variable, but HIV disease has a course and a chronology of its own, and the various stages of infection are characterized by different signs and symptoms.

The trajectory of HIV refers to the innumerable personal and social consequences of infection, and the work involved in managing illness. Our study shows that the illness trajectory of our respondents was shaped by both factors in their personal lives, and broader historical shifts, which we refer to as the personal and historical trajectories of HIV.

### PERSONAL TRAJECTORY OF HIV

Our intention in this report is to place the progression of HIV in the context of peoples' lives: what does life with HIV look like as people move in and out of relationships, as they age, as they become more knowledgeable about the virus and its treatment, as medications become more of a feature of their daily lives, as they work out new and ongoing relationships with health care providers, and as they assess their lives before and after diagnosis. These social realities and the course of HIV infection shape each other in complex and often unpredictable ways.

Much of our discussion in this report has focussed on respondents' *personal HIV trajectory*: how did they perceive and respond to the progression of their HIV infection in the context of their own lives. We have considered, for example, how they manage information about their diagnosis and their new self-definition as a person living with HIV/AIDS, and how did these decisions affect their relationships to others. We heard that changes in their health status – both improvements and deteriorations – can influence how they manage information about their HIV, and how these decisions sometimes factored into health care decisions.

Our respondents described how aging with HIV can bring unique personal challenges and, for some, certain advantages. For some of our respondents, living with HIV for two decades also meant confronting the vicissitudes of aging twenty years, and dealing with the often exhausting work of managing a long-term chronic infection. Their experience of living with HIV was tied to their sense of getting older and dealing with ill health over a period of many years, but living beyond what they had once imagined for themselves.

For most respondents, an HIV diagnosis means establishing new kinds of relationships with health and health care, needing to become knowledgeable about complicated health information, and becoming consumers of new medications that are simultaneously potentially life-threatening and life-saving. Respondents' perceptions of western medications often shift over time. For many, they once seemed to hold out the hope that HIV could be effectively conquered, but over time, this hope was tempered with a more measured appraisal of what the drugs could offer, and a better appreciation of the personal costs that can accompany medications.

Most respondents' relationships to their physicians were also characterized by some ambivalence. As they initiate antiretroviral treatment, respondents become reliant on the authority of their physician for information and access to western drugs. Expectations of health care providers can change as a result of time, age, and experience. Relating to an authoritarian physician can be a different experience when faced with the personal crisis of initial diagnosis than with a chronic condition many years later, when the crisis has passed, and when the individual has achieved a level of expertise and experience in dealing with HIV.

Responding to HIV in particular ways, for example, by carefully following physicians' advice or by conducting personal health research, can represent a means for respondents to maintain a sense of themselves as productive and responsible citizens. For those respondents who described morally dubious past behaviour, being a 'good PHA' can also be route to achieving this moral status.

## **HISTORICAL TRAJECTORY OF HIV**

Our study highlights another dimension of the illness trajectory that has not receive much attention: the *historical trajectory of HIV*. The HIV epidemic and the broad social and cultural context in which it is unfolding have not remained static over the past two decades. For example, as the contours of the epidemic have become clearer and as our collective understanding of the risk of contagion has increased, much of the earlier hysteria and stigma that surrounded the epidemic in the early and mid-1980s diminished. Our respondents remind us that AIDS-related stigma has not disappeared, but that it has changed over the course of time, as newly diagnosed individuals can feel blame for acquiring HIV in the face of current knowledge and prevention strategies. Deliberations on how to manage information about their HIV infection and how to maintain an identity as a moral and responsible PHA can change as a result of these historical shifts.

The advent of new medical technologies, such as HIV antibody tests or viral load tests, means that diagnosis is now more certain. This has implications for treatments, relationships to health care providers, relationships with others, planning a career, and so on. The natural history of HIV can be dramatically altered through new treatments. As the development of new medications means that many people in Canada are living longer with HIV, their sense of aging has also changed. Many can now imagine a future in a way that did not feel possible just a few years ago. Career plans, family relationships, and personal commitments of all kinds are viewed in a longer-term perspective. Yet, treatment regimens can come and go, giving and taking away hope, and often leaving respondents unsure of their long term future, regretful of earlier decisions, and confused and frustrated with changing and often conflicting information. As a result of changing treatment options, we did not hear any concern about conditions such as Kaposi sarcoma (KS) that Adam and Sears (1996) described in their study, although many of the concerns expressed by our respondents, such as those relating to how diarrhea can limit their activities, echo those described in this earlier research.

The historical trajectory of HIV also involves the evolving political and community context of the epidemic. Ideological shifts have taken place. Many now believe that PHAs cannot be passive consumers of health care, and many of our respondents accept that the course of HIV can be significantly altered by becoming actively involved in managing their own health through the use of various health promoting activities, such as improved diet or managing stress, and complementary approaches to health. As a result of this same ideological commitment, most of our respondents are engaged participants in the health care process, expecting information from their health providers and demanding to be the primary decision-maker in their own care. This commitment to engage and involve PHAs in their own care is now also reflected in HIV/AIDS services of various kinds.

## IMPLICATIONS

A key theme in our study is that it is valuable to consider the connections between personal and historical trajectories of HIV. In this regard, our study has a number of implications for people living with HIV, for health care providers and for policy makers.

***Managing Information.*** Even as the social environment has become more compassionate than it was early in the epidemic, our findings on stigma, disclosure and secrecy serve as a reminder to service providers and policy makers that stigma continues to be an important concern for PHAs. The experience of HIV as a disease with a history of being highly stigmatized influences the health care decisions of people with HIV/AIDS. Health care and service providers need to remember that many people with HIV/AIDS do not have many opportunities to talk about the problems they are facing regarding their health status for fear of being stigmatized. Creating such opportunities, and supporting individuals in their decisions about how to handle information about their HIV status can be an important role for health and social service providers.

***Aging.*** Over the last fifteen year HIV/AIDS has become defined more as a chronic disease. Many people with HIV/AIDS are learning about their infection earlier and have access to more effective treatments. In this environment, aging becomes a more salient and complicated issue as individuals make sense of living with a more chronic condition when perhaps they had once considered the disease to be terminal. Our findings concerning aging suggest that many PHAs may benefit from support in

reassessing their futures in light of changing medical options. Service providers should be attuned to the challenges of aging, and give individuals opportunities to talk about their future plans and concerns. They should also look for ways to support individuals for whom illness fatigue is an issue.

***Medications.*** Since the beginning of the HIV/AIDS epidemic, treatments have been a central concern for those infected. There have been many advancements in medications and potential new treatments on the horizon. Our findings suggest that some individuals become tired with dealing with HIV, its treatment, and the resultant side-effects over the long-term, but may have difficulty talking about their desire to stop treatment. Physicians and other service providers could play a useful role in helping these individuals consider the value of continuing treatment, and in supporting decisions to stop treatment without feeling like they are letting themselves and others down.

***Physician Authority.*** Physicians arguably have more to offer people with HIV/AIDS now than at any other time in the epidemic. In relationships with their doctors, our findings suggest that people with HIV/AIDS look not only for clinical expertise. People with HIV/AIDS see their doctors as being able to help them to properly live with the disease. In this way, respondents sought from their physicians both practical assistance and moral affirmation and approval. A greater awareness of the different types of authority that physicians have, and the impact of this authority for both providers and patients, can assist in improving existing health services for people with HIV/AIDS. Physicians may need to change their interactional approach as patient circumstances and preferences change.

***Responsibility and the Good PHA.*** At the same time the state is moving to place more responsibility for health on individual citizens, the community based AIDS movement has over the course of the epidemic advanced the importance of self-empowerment. While some PHAs welcome an increased involvement in their health care, some do not. Some PHAs experience this responsibility for their health as an additional burden at an already stressful time. Given this, it is important for policy makers and service providers to not reinforce too strongly the emphasis on active engagement in health care decisions as the only way to responsibly respond to HIV. The image of the 'good PHA' is but one approach to navigating HIV and its treatment.

In these five different areas our study sheds light on the complex interrelation between biological disease, respondents' personal lives, and historical context. Navigating HIV means carefully and thoughtfully responding to changing biological realities, aging bodies, developments in medical technology, evolving understandings of HIV, the unfolding of people's relationships and work lives, and even, shifting ideas of roles and responsibilities of individual citizens and the state.

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