

**Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS:
A Qualitative Study**

Project Undertaken By

The Canadian Working Group on HIV and Rehabilitation

Project Investigators

Robin Weir, R. N., Ph.D.

Joan Crook, R. N., Ph.D.

Christine Vanditelli-Chapman

October, 2003

Financial support provided by

The Office for Disability Issues, Human Resources Development Canada (HRDC)

Permission to reproduce: Portions of this report may be copied for use in nonprofit education and training. Content may not be edited and all copies must include the following text: “From the Unpredictable Episodes of Illness in the Experiences of Persons Living With HIV/AIDS: A Qualitative Study, a project undertaken by the Canadian Working Group on HIV and Rehabilitation, November 2003”. In addition this report and other related materials are available for downloading from the CWGHR website: www.hivandrehab.ca

ISBN 0-9734360-0-X © November 2003

Published by the Canadian Working Group on HIV and Rehabilitation (CWGHR)
333 Sherbourne Street, Toronto, ON, M5A 2S5
Phone: 416-324-4182, Fax: 416-324-4184
Email: cwghr@hivandrehab.ca

For additional copies of this manual please contact:

Canadian HIV/AIDS Information Centre
565 Carling Avenue, Suite 400, Ottawa, ON, K1Z 8R1
Phone Toll Free: 1-877-999-7740 or (613) 725-3434
Fax: (613) 725-1205
E-mail: aidssida@cpha.ca
E-order: www.aidssida.cpha.ca

TABLE OF CONTENTS

Prologue	iv
Abstract	viii
Background	1
Current State of Knowledge.....	2
Purpose of the Study	5
Methods.....	5
Recruitment of Participants	5
Design.....	7
Ethical Issues	9
Analysis	9
Findings.....	10
Demographics	10
Emerging Themes	12
Reflections on the diagnosis	13
Learning to Live.....	14
Riding the Roller Coaster of everyday life.....	16
Re-establishing a public face.....	18
Redefining self.....	20
Rebuilding Relationships	22
Family.....	24
Significant others.....	26
Friends	27
Health care professionals.....	32
Finding a way to feel productive	34
Work	35
The Conundrum: All or nothing at all	39
Summary	41
Conclusion	45
Acknowledgements.....	48
References.....	49

Epilogue 52

Appendices

 Conceptual Model of Cross Disability Issues

 Information Sheet

 Consent form

 Interview Guide

**Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS: A
Qualitative Study
A Prologue from the Advisory Committee**

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, charitable, nonprofit, multi-sector, organization that promotes innovation and excellence in rehabilitation in the context of HIV disease. In Canada, the profile of HIV disease is changing. At one time, HIV infection caused an often rapid decline in health, leading to death. While there is still no cure for HIV disease, today new drugs can slow disease progression and help people to live longer.¹ As HIV is complex, and experience and research are leading to new knowledge, people living with HIV disease, their families, caregivers and those involved in treatment, education and policy, face many challenges as a result of the unpredictable and episodic nature of the illness.

CWGHR conceptualizes [rehabilitation](#) in its broadest sense of reinsertion or full return to society for those living with HIV disease and its accompanying challenges. To achieve our [mandate and goals](#), CWGHR develops rehabilitation resources, new knowledge, and promotes awareness in a multi-sector collaboration with partners in the HIV/AIDS sector, rehabilitation professionals and with disability groups on issues of common concern.

Living longer with HIV often means dealing with impairments, activity limitations, and participation restrictions² that range from moderate or inconvenient, to severe and debilitating.

¹ Palella, F.J., Delaney, K.M., Moorman, A.C., Loveless, M.O., Fuhrer, J., Satten, G.A., Aschman, P.J., & Holmberg, S.D. (1998). Declining morbidity and mortality among patients with advanced HIV infection. *New England Journal of Medicine*. 338:853-860.

² World Health Organization. (2001). International Classification of Functioning, Disability and Health.

These challenges manifest themselves in physical, psychological, and social forms. As a result, they require a series of concerted and collaborative efforts in rehabilitation support and services.

Background on research into “episodic” and cross disability issues

Health care providers, institutions, and organizations often separate different disease groups into distinct “silos” (e.g., Multiple Sclerosis Society, Cancer Society, Arthritis Society, Canadian AIDS Society, etc.). These groups tend to operate autonomously, despite having overlapping experiences and common concerns.

As HIV disease has evolved into a longer term and often medically “manageable” condition for many people, CWGHR has had a growing sense that collaboration with other disability groups would be both informative and beneficial. It was felt that other “consumer” and “provider” groups with experience in episodic illness might make effective partners in the effort to affect change.

CWGHR conceived of a multi-phase Episodic / Cross Disability Project that would engage various disability groups and service providers in a discussion of commonalities between their “silos” and allow groups to explore possible collaborative work. There was also the intent to meet with policy makers to share collective concerns pertaining to episodic illness, as part of the project³.

“Phase I” of this project entitled “Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions” was completed in March 2002. It explored issues of similarity between the experiences of people living with HIV-related disability and people living with other chronic, episodic and unpredictable illness and/or disability. Results of this project

³ Proctor, P. (March, 2002). Looking Beyond the Silo: Disability Issues on HIV and Other Life-long Episodic Conditions, Final Report to the Canadian Working Group on HIV and Rehabilitation (CWGHR).

demonstrated a keen interest from a number of different organizations to participate in future collaborative work, and a list of suggested actions that would lend themselves to joint endeavours. Phase I also included a meeting with Dr. Carolyn Bennett, MP and Chair of the Parliamentary Sub-committee on the Status of Persons with Disabilities to discuss common themes pertaining to lifelong episodic illness emerging from the Project.

In “Phase II”, the main objective was to help CWGHR further define and better describe the episodic nature of HIV. Because there are many unknowns with respect to the episodic course of HIV illness (e.g. What are the impacts of living with uncertain or alternating periods of illness and wellness? Is the impact cumulative over time?), it would be beneficial to better understand the experience of living with HIV before continuing work with other disability groups.

A new advisory committee was struck by CWGHR to guide the direction of Phase II and to provide leadership to the research project. The Advisory Committee members were:

Kelly O’Brien; Physical Therapist, Project Coordinator of Phase II Episodic Disability Project, Department of Physical Therapy, University of Toronto, Toronto, Ontario.

Tom McAulay; CWGHR member and person living with HIV disease.

Vivia McCalla; Registered Nurse with the Home Hospice Community Program of Casey House, Toronto Ontario.

Peggy Proctor; Physiotherapy consultant, Saskatoon, Saskatchewan

Patty Solomon; Ph.D. P.T. Faculty of Health Sciences, McMaster University, Hamilton, Ontario

Peter Williams, Program Director, PHA Program, Ontario AIDS Network, Toronto, Ontario

Kate Reeve; Education Coordinator, CWGHR

Elisse Zack; Executive Director, CWGHR

Phase II was designed to seek out and listen to people living with HIV (via focus groups across the country) to learn more about their lived experience with the disease, especially in regards to the uncertain, unpredictable, episodic and fluctuating nature of the condition over time. Kate Reeve acted as the lead facilitator in all of the focus groups and Drs. Robin Weir and Joan Crook were hired as lead investigators.

From the outset of this phase of the Project, Advisory Committee members struggled with the use of appropriate language to use with focus group participants in asking them to describe their own experience(s). It was agreed that the word “episodic” may not be the best term, although this term had been increasingly used in previous CWGHR work. The committee chose to incorporate additional words that might help participants connect to our understanding of episodic and frame their own experiences with words that had meaning for them. This “other language” included “roller coaster”, “unpredictable”, “fluctuating”, “uncertain”, and “up and down”. It was hoped that more appropriate terms would be found through the Project itself to describe the episodic experience of living with HIV. Please refer to Appendix C of this report for a copy of the Interview Guide used in the focus group interviews.

The following report is a description of Phase II of this project. Results of Phase II will have implications for CWGHR’s work on rehabilitation programs and policy issues and inform the direction of this work in Phase III.

Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS: A Qualitative Study

ABSTRACT

Purpose: The purpose of this study was to examine the reality of living with HIV/AIDS, particularly the uncertain, unpredictable, episodic and fluctuating nature of this disease and the “roller-coaster-like” trajectory of that reality.

Methods: A grounded theory approach was used to explore the psychosocial processes that occurred over time for PHAs. Participants were recruited across Canada through outreach linkages with partner agencies of ASOs in a variety of geographic areas to ask them questions about their particular experiences in living with the unpredictable episodic illness. A qualitative approach was used in the form of small group, audiotaped, in-depth discussions led by a trained facilitator and co-facilitator.

Analysis: Transcriptions from the taped discussion groups underwent thematic analysis by multiple researchers to look for patterns of regularities, recurring ideas and experiences that linked or distinguished participants’ perspectives.

Results: Such knowledge provided an important foundation for exploring cross-disability issues pertaining to life-long episodic illness.

Uncertainty seemed to be a central feature of the life stories revealed by the participants living with the complexity of their illness, its unpredictable and ambiguous trajectory and the

complex and unproven efficacy and safety of treatments. The challenge was to find a balance between personal resources and environmental supports to find meaning to their lives.

BACKGROUND

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national, autonomous, multi-sectoral and multi-disciplinary working group formed in 1998 with a mission to promote improved quality of life for Canadians living with HIV disease through a national, co-ordinated multi-sectoral response to rehabilitation in the context of HIV. Its mandate includes the following two roles: a development and advisory role and a project and research funding role (Proctor, 2002).

As HIV disease has become a more lifelong, unpredictable but medically manageable condition, CWGHR identified the need for more collaboration with other disability groups in order to identify commonalities in their experiences and to share collective concerns.

As part of their research work and part of a larger CWGHR project, funded by the Office for Disability Issues (ODI) through Human Resources Development Canada (HRDC), a research project entitled Looking Beyond the Silos (CWGHR, 2002) was designed to bring people together to define disability and rehabilitation issues that were similar between people living with HIV related disability and people living with other chronic, episodic and unpredictable illnesses and/or disabilities. In addition, its purpose was to determine key aspects about the experience of living with the episodic life-long condition of HIV/AIDS.

Phase I of this project consisted of 3 components that included key informant interviews (N=10), with representations of national organizations primarily non-HIV groups dealing with life-long episodic illness/disability; a national one-day forum with invited key organizations (N=13), representing health care providers, rehabilitation specialists and volunteer groups; and a meeting between the CWGHR advisory group and the Federal Chair of the Sub Committee on the Status of Persons with Disabilities (Dr. Carolyn Bennett) regarding cross disability concerns.

A number of common issues were identified by the participants, which included: definitions of terms, care, treatment and support, workplace issues, income security and support, legislation and policy, stigma and prejudice, and education. These issues and themes confirmed the complexity of the question and interpretation and led to the development of a conceptual model to illustrate the various aspects or dimensions of disability (Appendix A) that would guide future cross disability work and to identify potential partners for collaboration (Proctor, 2001).

While this project provided an important foundation for exploring cross disability issues pertaining to life-long episodic illness, it was realized that there was a gap in our knowledge and understanding concerning how someone with HIV “copes with or manages the day to day struggles” that the unpredictable, and uncertain episodes of illness created for them. Therefore, prior to conducting further cross disability research, it was decided that the experiences of people with HIV/AIDS must first be elaborated.

A project Advisory Committee was established by the Canadian Working Group on HIV and Rehabilitation (CWGHR). Persons representing academia, PHAs, Community-Based AIDS Organizations (ASOs) across Canada guided the researchers in the development and conduct of the study.

CURRENT STATE OF KNOWLEDGE

The decrease in AIDS related mortality and morbidity is due to significant advances in the clinical care of people infected with HIV. The use of highly active antiretroviral therapies (HAART), including protease inhibitors (PIs), has been effective in suppressing HIV viral replication and reducing the incidence of opportunistic infections (Moatt et al, 2000). As a result, a growing number of HIV-infected persons remain without any clinical symptoms of

HIV-related morbidity and persons with AIDS are living longer and staying in better physical condition.

With earlier detection and more effective early intervention (Gallo, 1996; Siegal and Knauss, 1991) prolonged survival may mean high levels of uncertainty for longer spans of time for HIV-infected persons (Brashers et al, 1999). This uncertainty plays an important role in the illness experience due to the ambiguous patterns of symptoms, complex systems of treatment and care, insufficient information about diagnosis and unpredictable disease progression and prognosis (Brashers et al, 1999). AIDS has therefore become a chronic, progressive disorder requiring intensive medical management (O'Connell and Levinson, 1991)*. Unlike acute illness, a chronic condition is not an episode in a life, but rather it tends “to become the person’s very life (Pierret, 2000). Medication issues are prominent in this process. Whether or not to start the medication regimen is the first question to be addressed. Then having to take a large volume of medication with restrictions, such as with or without food or water or taking 2 hours before or after meals, structures their day around pills and serves as a reminder that they are unhealthy. Severe gastrointestinal side effects, lipodystrophy, hypercholesterolemia, diabetes and neurological disease accompany the decrease in opportunistic infections and hospitalization rates (Tiamson et al,2002; Bullers, 2001). These often crippling conditions are characterized by acute phases alternating with relative calm spells (Goldman, 2000). In place of the symptom-diagnosis-treatment-healing model, a different model has emerged that signals open, uncertain and unpredictable mental and physical challenges associated with the disease and the rapidly changing information about the illness and its treatment (Pierret, 2000). Because of the uncertain course and often complicated multi-system treatments, the mobilization of a network of family,

* The term “progressive disorder” may be interpreted and used differently by other authors and disability groups.

friends, health care professionals and services are required for their management. Living with a chronic disease requires a different view of the self and the meaning of the illness and one's life (Scandlyn, 2000). Many long term survivors have described the reorganization their lives have had to undergo as they realized that if they were going to die it might not be soon. In many respects, the uncertainty of chronic illness is as challenging as the knowledge that you will die (Scandlyn, 2000). One author and person living with AIDS (Goldman, 2000) describes his life as a "compromise between side-effects and an HIV regimen that seems to be keeping me alive". He describes this limbo state as a process of sustaining a body that will never be well but "may very well continue to be".

Over the past twenty years, the ways in which illness has been conceptualized by medical sociologists has shifted from an "outsider's" perspective of illness to the "insider" or subjective experience of the sufferer. While outsider views, like the sick role, illness behaviour and sickness careers have made an important impact on medical sociology, they have failed to reveal how illness is experienced and managed by those who have it (Conrad, 1990). Work is beginning to accumulate on the "insider" perspective on the chronic illness experience and includes concepts such as uncertainty, careers, stigma, as examples (Conrad, 1990).

Strauss et al (1984) have further conceptualized the illness experience in terms of the types of work that must be accomplished in all aspects of the person's life. They describe the variety of different kinds of work including: illness trajectory work (crisis work, symptom control work, regimen work) as well as other tasks such as every day life work and biographical work (Corbin and Strauss, 1985). How emotions are managed, especially with pain and exacerbations of illness and how they affect illness are largely unexplored issues ((Register, 1987). Central to the illness experience may be the meaning people attribute to it and how they

make sense of what is happening to them and to their bodies (Culnan, 1987). As some research has shown (McGuire and Cantor, 1987), issues of meaning may affect how people experience their illness and what they do about it.

There is a paucity of study and understanding about how people living with AIDS address their meaning of illness, particularly given this altered illness trajectory, that is the consequence of the disease, new treatment and care.

PURPOSE OF THE STUDY

The purpose of this second phase of the original cross disability study was to examine the experiences of people living with HIV/AIDS in regards to the uncertain, unpredictable, episodic and fluctuating nature of this disabling condition and the roller coaster-like trajectory of that reality. The findings are located within the sociological traditions of Corbin and Strauss (1986) in their work on illness trajectories in chronic illness. This conceptual orientation is consistent with CWGHR's interest in studying a wide range of chronic illnesses and will allow the eventual examination of how episodic, uncertain and unpredictable episodes of illness are shared or not among other chronic conditions.

METHODS

Recruitment of Participants

Following approval by McMaster University Research Ethics Board, potential participants were recruited through the co-ordinating efforts of the Education Co-ordinator of the Canadian Working Group on HIV and Rehabilitation (CWGHR). She had access to a national population through her work in planning and conducting regular workshops, across Canada, for

people living with HIV/AIDS (PHAs) and the many disciplines addressing rehabilitation issues in HIV/AIDS.

Partner organizations with CWGHR, such as AIDS Service Organizations, across Canada were advised of the study purpose and eligibility requirements of participants through written information (Appendix B) and through direct contact with CWGHR personnel. They were asked to advertise the project and the request for volunteer participants. Information sheets that described the study and its purpose provided the telephone contact number of the Education Co-ordinator of CWGHR who confirmed with the respondents their willingness, eligibility and interest in participating. Once eligibility had been confirmed, the co-ordinator advised the respondents of the date, time and place of the focus group.

Groups were scheduled at various sites across Canada on the basis of co-operative networks of agencies that were willing to participate in the recruitment process. The selection of geographic sites provided an urban/rural perspective within the selected participants.

Theoretical sampling was used to designate potential study participants. Eligibility criteria included that the potential participants:

- a) could speak and understand English
- b) were living with HIV/AIDS
- c) had at least one HIV related illness or were a long-term HIV/AIDS survivor (more than 10 yrs diagnosed with HIV)

These criteria allowed the selection of subjects who could illuminate the phenomenon (i.e. the episodic experience) being studied. For this study, 6 groups of 6 - 8 consenting participants were chosen to take part in the in-depth facilitator led discussions. Consenting and eligible study participants were asked to sign an informed consent form (Appendix B) prior to

the beginning of the focus group and to provide basic demographic information including their age, gender and length of time living with HIV/AIDS. Each participant received \$25 for his or her participation.

Design

As we were interested in understanding the lived experiences of a person living with AIDS, we employed a phenomenological and grounded theory method of inquiry. This study focused on using the grounded theory method for studying how the symptoms and exacerbations of their illness affected their psychosocial and daily life management of their disease. Through the focus group format, this method provided an opportunity “to see the work through the eyes of the target group” (Stillman, 1991). Through the communicative benefits of group dynamics (Stillman, 1991) the focus group method was useful to explore social and communication issues and examined the cultural construction of experience by tapping into people’s assumptions and framework to draw out how and why they thought as they did (Kitzinger, 1984). Research questions were developed to explore the meaning and reflections of a particular experience and to stimulate discussion that would illicit accounts of the effects of uncertainty and unpredictability of episodic symptoms and illnesses on their lives. Participants were asked a variety of open-ended questions. Probe and follow-up questions were included to clarify issues and to validate researcher interpretations. These questions were tested with a volunteer group of support workers in an ASO, prior to the study, for clarity and relevance and refined with the feedback (Appendix D). The grounded theory approach was used to explore the social processes that occurred over time within phases or stages with the goal of contributing to theory. The

qualitative approach was in the form of small group, audio taped, in-depth discussions led by a trained facilitator and co-facilitator.

To maintain consistency in group methods and data collection, all groups were facilitated by the same trained facilitator while the co-facilitator varied across groups. At the end of each session, the facilitator and co-facilitator debriefed together in a private location with a review of their impressions and field notes of the session to compare their notes. The audiotapes from the in-depth interviews were transcribed verbatim, and facilitators and co-facilitators had the opportunity to check the accuracy of their content.

The role of the facilitator was to stimulate and guide the group. She was aware of the dynamics of the group and was able to exercise a mild unobtrusive guide to the flow of the conversation. Maintaining group enthusiasm and interest for the topic plus a sense of timing for the mood of the group and the appropriateness of discussion alternatives were essential.

The co-facilitator made written field notes in an attempt to capture brief comments of the participants – especially those comments that might be quotable. This note taking did not interfere with the spontaneous nature of the group interview but captured the central points of the discussion. They served as a backup should the tape recorder have failed to function or background noise drown out individual voices on tape.

The tape recording equipment was set in plain sight before the meeting began. The importance of the recorder was mentioned at the beginning of the group discussion and was introduced as a tool to help capture everyone's comments and to assure participants that no names would be included in reports. Participants were encouraged to speak one at a time to avoid "garbling" on the tape.

Ethical Issues

Written, informed consent was obtained by the group facilitator from each participant prior to each group discussion (Appendix B). Consenting participants did not need to sign their own name to protect their confidentiality. Only the research team had access to the interview tapes and typed transcripts. Tapes were destroyed once they were transcribed. Transcriptions of focus groups were kept in a locked location, accessible only to the research team until the final report of the study was produced. All responses are confidential. Any quotations used in any report for publication are attributed anonymously. Audiotapes were not available to participants for review in order to ensure the confidential nature of individual comments on the tape. Consenting subjects were advised that they could terminate their participation in the study at any time (i.e. leave the group).

Potential and consenting participants were advised that the purpose of the group was not to provide counselling but rather to explore participants' experiences. Should the group discussion have stimulated sad feelings and reflections to the extent that a member would need to leave the group, the co-facilitator provided access to appropriate resources. Partner agencies in the particular area of the focus group provided relevant backup staff resources for to the focus group facilitator to refer to should any of the participants require assistance.

Analysis

Data obtained from the group discussions were transcribed and entered into the NVIVO computer program for qualitative analysis. The researchers used latent content analysis (Babbie, 1995) which involved an independent review of the group transcripts as a whole for an overall understanding and to identify general categories of content. The researchers then met and

reviewed their independent lists to develop a central set of preliminary categories followed by repeated reading of the texts to look for patterns of regularities, recurring ideas and experiences that linked or distinguished participants' perspectives. Key ideas were assigned code names, which were then grouped into descriptive categories. After extensive review, these categories were grouped under themes which reflected concepts to which the groupings were attached. Subsequently, the original transcripts were reviewed and coded using the categories and themes. Differences between authors in coding were resolved by mutual agreement based on a review of transcript segments.

FINDINGS

Demographics

Six focus groups were conducted across Canada between March 7 and April 16, 2003. The majority (86%) of participants were middle-aged, male, long-term survivors of HIV/AIDS. We attempted to include participants from rural and urban areas through the choice of cities and knowledge of areas that each ASO served. Study participants were from a variety of ethnic groups and had a range of educational backgrounds with $\frac{3}{4}$ of the sample having completed high school and beyond.

There seemed to be three different categories of participants: those diagnosed many years ago who had 'grown up' with the progression of the disease and its treatment with drugs and therapies and who had contracted HIV through sexual relations; those who had contracted HIV by drug use through sharing of needles and were diagnosed within the past 6 years; and those who contracted the illness in other ways, such as through tainted blood transfusions, or from a partner who had a tainted blood transfusion.

Table 1
Demographic Information of Respondents

Variable	Totals (N=44)
Age (Years)	
Range	28 - 77
Mean	43.08
SD	3.27
Gender	
Male	38
Female	6
Length of Time since Diagnosis (years)	
Range	4 - 20
Mean	12.07
SD	0.93
Description of current living area	
Metropolitan	24
Urban	15
Rural	5
Identify with a particular ethnic group	
Yes	14
No	28
Not answered	2
Level of Education	
High school/some college/courses	15
College	13
Post-College Diploma	1
University Degree	3
Incomplete or N/A	11
Health Status	
Excellent	3
Very Good	16
Good	16
Fair	7
Poor	1
Not answered	1

Emerging Themes

The initial questions about the experience of living with the “ups and downs” of their disease, produced categories of information which included: a) learning to live, b) re-establishing a public face and rebuilding relationships, and c) finding a way to be productive. The first category (a) emerged from participant’s discussion of the impact of their diagnosis of HIV and how they coped. The other 2 categories (b,c) represent the challenges and their experiences with reconstructing their lives.

During the analysis of the data, it became clear that, while specific individual experiences differed, there was an emergence of common experiences and themes. Participants were linked by more than a disease as they shared a special bond, through the group process that they were not alone in their experiences, or how they were feeling, and learned that what they were experiencing was “normal”. Themes that became common across the groups included reflections on their diagnosis and the symptoms and side effects that they experienced, to struggles about presenting and revealing a public face, to the importance of the definition of the disease for self and the redefinition of self, to the challenges relating to relationships, to issues about paid work and returning to work.

Most of the participants of this study (70%) had an HIV positive diagnosis for more than 10 years. They were from an era in medical history when the only thing related to being HIV positive was most certainly death. They were from a time when the first thing that you did after being diagnosed was to begin to make funeral arrangements, detach yourself from now meaningless time constraints and limitations and live for the moment because you did not know how many more you had to live. They were also from a time when there were great advances in medical treatment of HIV disease, turning the tide from the certainty of death to the potential to

live. What follows is how the participants lived out those moments, with the ups and downs, the gains and the losses, and the challenges of living with a recently defined chronic illness.

Reflections on the diagnosis

As mentioned above, most of the participants were diagnosed many years ago, during the time when treatment and drug regimes were in their infancy, and the knowledge that the diagnosis of HIV positive surely meant a death sentence. The diagnosis of death impacted people in many ways. Some went right out and prepared their funeral arrangements so that their family and friends did not have to cope with that:

“made all my plans, like the funeral, did the will, notified the family...the whole shebang”;

while others took the diagnosis as a release from the everyday responsibilities of living:

there was a certain freedom in that you were going to go...you weren't responsible for anything...and you weren't capable...but you didn't mind 'cause you couldn't handle it anyway.”

All informants talked about how the diagnosis made them redefine their outlook on life and so rather than working and planning for the future which they now ‘know’ they will not have, they began to live in the moment, one day at a time, as if everyday was their last.

While living everyday as their last seemed to mean a “duty-free” outlook on life, it was in fact quite the opposite. Living everyday as the last meant that many deferred decision making to their partner, or others in their lives, since the decisions were not going to affect them anyway. This was most poignantly illustrated when one participant talked about purchasing things and not having to worry about warranties because they themselves would expire long before the warranty did:

“the beginning part is that phase where you don’t care about buying appliances or when you buy the appliances you don’t care about the warranties...and then when you get over that and you do care about the warranties in the back of your mind...you realize...”

Deferring decision making to significant others in their lives, in a sense meant giving up some control, only to have to struggle to regain that control months, sometimes years later, once they internalized the fact that they were going to live. Living in the moment meant not making plans or commitments, not investing in one self, or in relationships with others, or as one participant explained it:

“I go through the motions of life but am not really living”.

Learning to live

“The diagnosis” seems like a logical place to start the story, and yet it was not an overriding theme throughout the discussion. The discussion focused more around the impact of being HIV positive on the emotional, physical, financial and practical aspects of their lives, and the “bumps” in the road that made their experience unique to people diagnosed HIV positive. Being diagnosed with a disease that is supposed to kill you is difficult enough to deal with, but then learning that you have been sentenced to life is a concept that is not as easy to accept as it might seem.

With the improvement of drug regimes and the management of acute episodes of illness related to being HIV positive, so did the life expectancy of those diagnosed. These advancements meant that those diagnosed had to re-evaluate their outlook on their life and life expectancy. They had initially resigned themselves to living one day at a time, ‘as if tomorrow would never come’:

“it’s hard to go from expecting to die and then all of a sudden realizing, well, maybe that’s not going to be the case...it’s a hard transition to make...to do that turnaround was like you’d been reborn...and it was really scary”

With the change in the trajectory of their illness from a certain death to an uncertain future of chronicity, each participant was challenged now by the choices to be made. S/he could either continue to 'live' as s/he had been since diagnosis, one day at a time, going through the motions of living, but not really being alive, or, s/he could accept that this was something that s/he was going to have to live with for the rest of his life, and figure out a way to incorporate all that comes with being HIV positive into his life:

“you’ve been so long getting to that point...that when you did realize that you were going to have to take hold of yourself...I found it awful...I felt right out of place...I mean you’ve lost all your self-assurance...I mean all of that was gone...and I started out having to relearn really, how to talk to people.”

Learning how to live with this longer lasting illness trajectory rather than an imminently fatal one was not an easy adjustment. This meant that the participants now had to try to reclaim their place in society, the place that they had relinquished when diagnosed. This was quite a challenge as sometimes this realization did not come for years, and some still struggle with it today. Reclaiming their place in society meant that they now had to rebuild relationships, re-establish a public face, find a way to be 'productive' society members, and ultimately learn to manage their lives armed with the knowledge of medication, fluctuating symptoms and the realities of living with a chronic illness.

The work that goes into day-to-day living with HIV is not always recognized, for the day-to-day effort and concentrated, complicated ongoing activities it takes to maintain the semblance of a 'normal' life and do the things that 'normal' people do:

“...and when depression zaps your ability, first all you’re feeling...is it even worthwhile to bother and second, your capacity and energy to do the work of day-to-day living...has left you open for all sorts of things...so if you’re not able to look after yourself...it just makes you realize what a complicated business it is getting from day to day, taking the right medications, eating the right food, getting enough sleep...that even if your life is healthy in all its aspects, it doesn’t happen all by itself...”

Riding the Roller Coaster of Everyday Life

The onset, or triggering of symptoms became a big focus for most participants. They found themselves living with this fear always in the shadows, which sometimes meant major lifestyle changes to manage symptoms or side effects:

“but you don’t know when you’re going to get sick or how long you’re going to be sick for...it’s very unpredictable...for me it just comes out of nowhere. I can be sitting on the couch and my girlfriend will look at me and say ‘what’s wrong?’ ...and all of a sudden it will just happen...it will be there.”

With such uncertainty of symptoms and side effects, the very fabric of social life was in limbo:

“you don’t even think of making plans because you just don’t know if you’re getting up off this down or, you know...and when you’re really getting down, there’s people who don’t understand...”

A further source of uncertainty concerned how to even interpret the symptoms or side effects that they were experiencing. Was it only a cold or headache or an upset stomach, or was it the precursor to another episode of illness?

“...and people coughing when you’re in a public vehicle or something...I have a fear that I never had before...you know it is rude that you blew in my face...now I actually feel tightening in the chest and you remind yourself of the danger that you’re facing...and it’s not...some of it is rational...a lot of it isn’t...and you’re living in those kind of fears that really are nonsense...but they’re really part of who you are these days.”

While knowledge might be gained overtime about the course of some of these episodes of illness, there was always the fear lurking in the background of whether or not this was the time that they would not get better:

“all the way through and I’m sure there was probably somewhere in my head...I was going...ok...is this the beginning of the end, kind of thing...especially if it’s a long period where you don’t have the energy and you don’t have that get up and go...you start to wonder...is this that moment where it’s switching?”

The beginning of the end was seen as a downward tumble often prompting participants to seek out medical interventions in attempts to halt the avalanche. For some it was clear that when

the end was in sight they would “just end it” instead of having to endure prolonged suffering. Those who were making the decision to end their lives when the symptoms felt unmanageable to them, were participants who were diagnosed more recently and said they were well aware of the potential and limitations of the current drugs. Participants who were veterans seemed more willing to try new and different medications in order to prolong their lives. The veterans reported that they had the historical knowledge and experience of when HIV was an imminent death sentence, and therefore had placed more hope and faith in new medical procedures and drugs. The challenge for all participants was the sorting out of regular everyday symptoms versus symptoms that needed attention.

For some, the fear was not only “if and when” to seek medical assistance for managing their symptoms, but also “where” to go for such assistance:

“we live in a rural area...there is nobody where we are...it’s very redneck...so you don’t want to tell nobody we’re HIV there...but being out there when there’s really not a lot of support of community access to the knowledge of HIV and AIDS...then where do you go from there?”

Coping with these uncertainties required some participants to reframe their expectations and experiences:

“I think that I am trying to achieve a state of less control...when I say less control I mean accepting unpredictability that anything can happen at any time...and being fine with that.”

Similarly, to manage the side effects of their medication regimen, many resolved their conflict with acceptance of what they believed was a trade-off of side effects versus health:

“I just have to put up with the side effects. If I want to stay on good therapy...I have to put up with the side effects.”

The struggle to find effective medications was one that was ongoing. Participants talked about the need to change medications because their body ultimately became immune to specific medications, meaning they therefore had to go through the adjustments all over again:

“When I first went on to the previous therapy I noticed that I had to let my body adjust to these medications, and of course there's side effects along with that. And just recently, within the last couple of months, I've been switched to another therapy because the other therapy was becoming ineffective and my body's still adjusting now”.

Another participant told about dealing with the difficulty of medication changes and the challenge of the time it took the body to adjust:

“Yeah. They've changed my medications three times on me because my body's immune to it. So now I'm on my third and I'm just adjusting to it now. So yeah it's been a roller coaster for me too”.

Medication changes had the potential to be viewed as a positive intervention, yet the changes were surrounded by uncertainty and, for the patient, the time of adjustment might have gone unrewarded if the medication proved to be an ineffective addition to their original regimen:

“I think the roller coaster only really occurs when I switch drugs because I ask the question, are these drugs going to work and if so...what side effects will I get?”

Yet despite all of the struggles and side-effects participants acknowledged that most times it was worth the struggle because they found:

“health-wise, that once you do go on to the therapies your health does increase. You do better once your body has adjusted”.

Re-establishing a Public Face

All participants, working or not, young, old, male, female, discussed the concept of having to put on different masks depending on with whom they were interacting. The effort that went into “looking and participating” as members of society was one of the most difficult and

challenging efforts. The challenge of normal participation in society meant the management of their resources (energy level, symptom control, emotional strength) so that they were at their optimum place when they engaged in “the real world”.

For those in the paid workforce, there was a lot of discussion around the emotional work of needing to wear the mask of normalcy, as they did not want most of their co-workers to know that they were HIV positive. Participants revealed their diagnosis to only a select number of co-workers in their attempt to maintain and manage their public identity in the face of the stigma that still surrounds such a diagnosis.

The greatest challenge in terms of resource management and choosing to participate in society was the varying levels of fatigue and energy loss. Participants discussed the symptom of fatigue and limited energy:

“I think that my ups and downs may not be as dramatic as some people’s...but they’ve certainly been there and for me, it’s mostly a matter of energy level. I can put out a fair amount of intellectual and physical energy for a fair period of time but it’s you know...it is like a battery that is sometimes charged and sometimes not and when it runs out, it runs out...there’s no earthly way that I can do anything with it...it’s another one of those examples that gets met with different reactions because when I say, man I really don’t feel like getting out of bed today, others just say, yeah, don’t we all...”

Trying to “parcel” out their energy resource and meet their own expectations required significant work and planning. There were times when participants had to make trade-offs, which sometimes impacted their health in a negative way; hence always requiring re-evaluation and concern:

“like right now I’m really busy (working)...and so I’m not doing the things that were really good for me, like yoga three times a week and going to the gym three times a week and all those kinds of things...it was like oh I can be busy and I can keep these things up... but I would immediately sacrifice my own self care in order to be there and be busy because that really boosts the self-esteem... it just seems like I have to pick one or the other...I can’t seem to find a balance of both...”

The pressure for participants to manage their limited energy resources was influenced by their great performance. They had become so efficient at picking and choosing their interactions and participation in society that there was almost never any doubt that they “should” be full participants. In other words, they were so good at convincing people that they were fine that others’ expectations of them did not falter. This meant that once others tuned into their limited output, they then became the target of judgement for being lazy for choosing not to participate, or do something extra whether at work or play. These judgement calls meant either taking the time and effort to explain, or what some might say, expose themselves, or keeping their diagnosis and challenges to themselves and ultimately having to deal with the emotional backlash of others:

“I have to really push myself to get out of the house because there are some days that I just don’t want to ... it’s got to the point where I’ve actually cut down my work hours...and we are allowed to pick our work for 3 months and I take the least amount of hours that I can and I don’t even work overtime anymore. When I first started there I think it was a stretch of about 2, 3 months that I worked every day without a day off. I can’t do that anymore. And my boss still is calling. He doesn’t know but the company doctor knows and human resources but my boss he’s always calling me can you work extra, can you do this. Thank God I’ve got an answering machine so I let that take it”

Redefining self

As discussed above, all participants discussed the challenge to redefine their sense of self once they decided that they were going to accept the challenge of living with this longer lasting state of illness. Redefining self was a necessity if they were going to attempt to reclaim a place in society for they were now looking at the world through the lenses of the disease. Learning what it meant to live with a chronic illness occurred through managing their daily lives. For some, developing new ways of thinking about themselves, lent a sense of control and belonging:

“right now I just think of it as my best friend. I go to bed with it, I wake up with it...there’s no shaking it, so, in order to take care of myself, I’ve got to nurture and love it. That’s my attitude...it’s helpful...it’s my best friend.”

Whereas for others, their illness remained a continuing source of stress and challenge:

“I regard HIV as a thief...it stole from me. It still steals from me. So on the good days, the up days, the thief has not come in...the windows aren’t broken...nothing’s happened...I’ve gone through the whole of the good day waiting for the other shoe to drop...but I recognize that at any minute the window might break.”

From the point of diagnosis to the point of re-entrance into society, the world that they chose to construct was different for each participant, just as the experience of symptoms and side effects were individualized. Participants recognized that how one deals with these issues is somewhat dependent on “who you were before the diagnosis”. So individuals who had developed coping mechanisms through their other life experiences were able to utilize them to deal with the issue at hand. This also meant that those who had other issues in their lives, whether physical or emotional, still had to manage their pre-existing conditions on top of the management of the “new” diagnosis.

Many participants discussed the fact that the HIV positive diagnosis seemed to magnify other issues in their lives, depression being impacted the most. Participants shared the fact that often it was the depression that was the most difficult to deal with rather than the physical symptoms:

“I mean when you’re dealing with a physical illness you conditioned yourself from it. It’s not a shame or a stigma to have a broken leg or a cold...but if you are suffering from depression then you’re a weakling and a loser...and if only you were a better stronger, you know, tougher person...”

Depression was a huge issue for most participants. Most felt that their depression was perhaps the greatest challenge that they faced as they recognized that all of the other losses influenced their mental health and desire to interact with others and society. Those who identified

depression as a challenge were able to find inspiration from their relationships with others who in their opinion were managing their HIV status and, therefore, able to live a positive and happy life. The issue of depression and impact on the sense of self was one that weaves its way through all of the intricacies of living with HIV. Because of this infiltration, it is important to keep in mind that unlike other symptoms that seemed to come and go, depression was one that was forever present, actually or “in the wings”, influencing or impacting on every experience.

Rebuilding Relationships

Participants at every stage of illness and diagnosis had to make decisions regarding to whom they were going to allow access and the amount of access to their “HIV positive world”. In making these decisions they had to take 3 factors into consideration: access, choice and control. Participants had to make decisions regarding whom they were going to allow access to their “HIV+ world” and the amount of access. They allowed different people into their lives at different levels of intimacy and at least attempted to maintain control of their relationship with others. Finally there was the concept of choice. This referred to whether the people in the participants’ lives chose to accept the access that they were given and how they chose to act or react. While participants made every attempt to control access they did, at times, find themselves in situations where that control had been taken out of their hands.

There seemed to be four distinct categories of relationships in the participants lives: family, significant others, friends and professionals (medical and employment related). Within these groups there were varying types of access given, as well as varying responses or choices made by ‘the other’. Similar to an average person’s life, it seemed that there were very few others who were provided full access, that is, allowing someone to come and go as they pleased,

and to witness the ups and downs of everyday life. Most participants had people in their lives who fell somewhere in the continuum between full and no access.

Deciding on levels and types of access was not a constant. Since situations, symptoms and relationships were ever changing, they often had to be ‘re-evaluated’. Therefore maintaining and forming relationships for these participants was a constant process of measuring investments, risks and losses. Different levels of investment in relationships depended on what stage they were at in their life with HIV. Participants who were diagnosed many years ago, at a time when treatments were not as well known or advanced, made the decision to invest little to nothing because they were not going to be around much longer. These participants, whom we call veterans, did not feel that they were going to live long enough, so they stopped investing in relationships and involving themselves in other peoples’ lives. Part of their lack of investment played out in their withdrawal from decision-making:

“the first 6 years it was pretty shaky and I sort of gave up and thought I was going to die and didn’t. I’m in a long-term relationship and I didn’t voice my opinion what to do with the house or anything like that. So I sort of just withdrew the decision-making”.

As they came to the realization that they were going to live, they started to realize what they had given up and now had to work on re-establishing bonds, trust and their social status:

“now ...after 6 years of it...I’m trying to reclaim it back”.

As participants described their relationships, we gained an intimate view of how they decided who gained access to their lives, and the struggles that they went through in making those decisions. We also learned about the challenges they had in attempting to control different types of access in their relationships. And finally, they revealed both the positive experiences, and the raw emotions when having to cope with the choices the people in their lives made with the access they have been given.

Family

Family situations for participants varied. Some participants were involved in long-term relationships prior to and following diagnosis, whereas others were still in search of such a relationship. Some participants had immediate and extended family active in their lives, while others described relationships that were strained or absent. Access, or the issue of boundaries and the filtering of information proved to be a challenge that consumed both time and precious energy.

Participants who had established family relations, whether it was with significant others or other immediate family, generally reported that they experienced positive support in their relationships:

“I’m lucky. I have family: my daughter and grandchildren and my son-in-law is a wonderful human being. That’s very important. I’m loved and they need me and I need them but they need me. Then you see that is very, very important. And they really understand”, “...and just the way I was treated by my family I wasn’t really coddled like I was on my last days or whatever, I was just treated as a member of the family when at that time people were pulling their kids away from people who were HIV positive”.

While many participants had great support and relationships with family, there was a great deal of discussion around having/wanting to “protect” them from worrying:

“ I don’t see why I should tell them. They have enough worries”, “my family are completely protected from my ups and downs. I would not let them see or know of a down if I could help it”.

For these participants, protecting their families meant saving their loved ones grief and worry.

Other participants protected their families from bad episodes, not as an attempt to save them from emotional upheaval, but rather to save themselves from the reactions of others:

“It’s a huge amount of work to be constantly smoothing out and saying I’m not going to drop dead, I’m going to be okay...get out of my face, please.”

Maintaining others' personal health through the filtering or withholding of information, for some participants, was one way that they protected themselves and attempted to maintain control over choices that family members made with the more open access initially provided:

“you don't want to show too much of your symptoms because you're trying to maintain other people's health. And even though you have a need to talk about it, you can't because of how other people are going to deal with it”.

Some participants said that, in some of their family relationships, the access that they initially had given to their lives had to be re-evaluated because of some of the choices that family members made. When the main involvement of a relationship became focused on illness, participants became overwhelmed. In order to protect themselves from this type of relationship focus they learned to limit access, often keeping day-to-day symptoms to themselves:

“they get very concerned if I even just say I'm tired. Well why are you tired, what's wrong? I feel like they're jumping on me and I'll just say, chill out, I'm just tired”.

When the shift from open access to more limited access happened, family members reacted with increasing concern:

“Concern is wonderful but at some point it becomes ... I have to say almost pathological. It really does get to the point where it's like they don't want to hear that they don't need to be needed”.

There were some participants who re-evaluated family access and instead of reducing it, increased it, but only after having to educate them:

“my mother and sister, when they first found out I had it, they didn't even want me to visit. I'd go out and visit, they put hot water and javex in the sink if I used their cup or a fork or spoon. So I got 6 months into having it and turned around and I said, come up here, I've got all the information, I said, here, I won't talk until you read all this information and see where you stand. So now they give me all the support I need”.

The other extreme of family relations that our participants talked about focused on strained relations, or no relationship at all. Some participants explained that they had little to no

contact with their families prior to, or following diagnosis, so there was not much change. Other participants talked about the strain that the diagnosis put on their family relations:

“I don’t need the BS about being HIV positive from you so I’m going to write you off”.

Significant others

While participants discussed the value of the support they received from their family and friends, there was the acknowledgement that there was nothing that could replace the love, support and relationship of a significant other:

“well you know your family loves you and stuff but it’s different when you have a partner or a girlfriend or a boyfriend”.

Some participants were in long-term relationships at the time of diagnosis. These participants did not report any rifts in the relationship as a result of being diagnosed HIV positive. Participants who were not in long-term relationships talked about having great difficulty in finding and maintaining intimate relationships:

“I try to find a girlfriend and you’ve got to tell them that you’re HIV and it’s just I can’t get a girlfriend or nothing, it’s just crazy. It’s like you’re alone all the time. I’ve really had a rough time”.

Some participants have given up on finding a partner because they were not willing to get hurt again:

“once we got too close; I don’t need to be hurt further. I don’t want to be disappointed”.

Participants who were still searching for a partner, talked about the fact that they needed to ease their potential or new partner into the realities of HIV:

“And even still when I start to date somebody new for the first time, if they’re not positive, then I kind of break them in slowly into my HIV. I don’t tell them how long I’ve been positive or how long I’ve been out of work and I don’t let them see the pills right up front. I sort of ... it’s like a stages thing”.

They talked about easing them in slowly in order not to frighten off the potential partner.

While some participants thought the slow approach was best, others believed that telling all, right up front would help to protect them from loss when the time finally came for them to reveal their status. These participants talked about being honest all along, but somehow realized through experience, that the intellectual understanding of the effects of HIV and AIDS was easy enough to discount until the relationship reached the point of physical intimacy:

“...they don’t have an understanding of what’s going on even though they try. They say things like I’m ok with it, until you’re like in bed naked and then all of a sudden that ugly virus and those body fluids are right in their face literally and they 180 on you in the middle of sex. I find that really difficult to deal with”.

Many participants discussed the loss of physical intimacy and the impact that this loss had on their lives overall. The impact of the loss of physical intimacy meant, for most participants, feelings of physical isolation and loneliness. While they acknowledged that the intellectual and emotional intimacy they enjoyed enriched their lives, they still felt the loss of touch and the impact of that loss on their relationships and their sense of self:

“You’re living in a don’t touch me but touch me. There is an intimacy intellectually of what used to be physical and it seems to me that you’re only living half because to me to be whole, you have to be the whole pie or none of it. And I’m living there in a lifetime of just half a pie and I have to be able and successful with it, and I’m not happy with it and I don’t grieve it. I’m passed that but it’s forever there. It’s the reality that it’s no longer possible”

Friends

The discussion around friendships focused on four different issues: the current status of friendships, challenges to opportunities to meet friends, finding and creating opportunities, and building and maintaining a support system.

The loss of friendships and the forming of new ones were a focus for some participants. The loss of friends meant two different things: the loss or death of friends, mostly from the

disease; or the loss of friends who could not handle the realities of their diagnosis. Some participants lived through a time when all of their friends were HIV positive, and they had to bury most of them:

“I was diagnosed 18 years ago, just over 18 years ago...so I was the second person in my circle of friends...that circle of friends I’ve buried”.

Another participant poignantly described the consequences:

“sad thing is that you spent your teens and 20s developing what I call your friendship web, your infrastructure...and then this virus comes around and wipes them all out...and by the time you realize, by the time it’s all over, you’re all alone...”

As a result of the emotional losses participants have had to face through burying friends, some made the decision that they would not have new friends that were HIV positive:

“most of my friends died, I vowed not to have positive friends again”.

This decision was made in order to protect themselves from the losses and from a reminder of their potential realities. Most found it difficult to keep this promise to themselves as they continued to seek out new relationships.

The other kind of loss that participants talked about was the loss of friends who reacted to either the diagnosis or the circumstances surrounding it. What follows is a description about what happened when participants gave their friends access to their lives and information surrounding their diagnosis, and the choices that they made. Participants described how they felt that friends who were not HIV positive, or had not experienced symptoms, had a more difficult time understanding the ups and downs:

“Yeah I do understand that when you’re talking to people, especially people that are negative, when you’re trying to tell them you’re having a bad day and all they want to do is go out and party and have fun, they don’t get it at all”.

Participants talked about friends leaving at different points in their lives. Some had friends leave as soon as they found out about the diagnosis:

“I found out who my true friends were and found out who weren’t. It was a very painful experience”.

Others talked about friends who said they were okay with everything until symptoms and side effects became visible:

“they see me, like all of a sudden I look different now, and they don’t want to come near you”.

Dealing with the loss of friends was difficult, but those friends who stuck around provided participants with support through the ups and downs, and on a daily basis:

“those who were very receptive to me, they were very supportive and I still have them as friends to this day. They’ve been very supportive at that time when I was really, really sick”.

Many participants talked about the difficulties in making friends and the challenges to opportunities. Some of the challenges to opportunities to meet new people included: stages of life, ‘normal’ social conversations/social icebreakers, fluctuating symptoms and disclosure. Some participants acknowledged that they were at an age when they should already have had their group of friends:

“as I get older, like most people, my life has been departmentalized; and there’s a whole section of friends that don’t exist any more. And I might have had a hundred friends, I have three – that’s different”.

Part of this challenge was because of their early departure from the work world:

“your age group are already established, their lives are full. You’re not 20 anymore when you have a lot more time. You’re in your late 30s, your 40s, your 50s, and people in your age that you expect to be able to socialize and connect with because they’re from your generation, well their lives are full”.

The challenges to meeting people seemed to be mostly a result of our participants not being comfortable with their social place, and how it compared to ‘the norm’. Because many of them were not working they found it difficult to be in an environment where meeting new people meant small talk and social icebreakers:

“I absolutely hate going to social events or dinner parties, that kind of stuff, where people don’t already know me and what my life is like because they inevitably...somebody turns and says, so what do you do for a living? So I hate that question with a passion to the point that I’ve told my friends if I’m going to be the new person at the table, don’t invite me, I don’t want to go”.

Along with the lack of comfort with social status, participants also struggled with revealing to new friends that they were HIV positive:

“They’re either afraid of us or they’re not. I mean I’ve certainly worried myself over this a considerable amount, disclosure or not disclosure, whether it’s for friends or for sexual partners. Either they’re going to react positively or they’re not. They’re going to accept it or they’re not. And whether I worry about it, it’s not going to make any difference about it and my experience has taught me that the sooner they know the truth about you the better. The sooner I get it over with the better it is”.

While in most cases participants discussed the loss of friends as a result of choices made by other people, in a few cases, participants revealed that they were the ones who had to end the relationship:

“early on when I had friends in the 80s that thought HIV was the biggest sin in the world, or the face of the earth, I figured I didn’t need them for friends anymore. I was probably better off without them”, “I had some friends that I finally had to choose to get rid of in my life. I mean they were negative in subtle ways. I mean it’s like I’ll try and quit smoking, but oh here have one. Just little things like that that I just realized, you know what, this is not in my path of healing, remove the negativity from your life, and since then ... I mean it was hard, I cut them out”.

These participants felt that in order to promote healing and acceptance of their diagnosis they had to get rid of negative influences, and people that had the potential to drag them down.

Much of the discussion surrounding friendships, and loss of friendships had to do with lack of understanding and willingness to cope with the effects of a friend being HIV positive. Friends seemed to be categorized as either HIV positive or HIV negative. Participants talked about not wanting to have friends that were positive because there was too much to lose, but having friends that were negative seemed to lead to more misunderstanding. Ultimately most

participants ended up realizing that they needed to find a place where the challenges discussed above did not exist and they were able to “*just be themselves [sic]*”.

In attempting to address the issue of finding new friends they described the different ways they attempted to find and create new social opportunities. The first, and perhaps most obvious suggestion for meeting new people who may be able to provide understanding were support groups. Some participants talked about attending support groups when they were first diagnosed, but found that they had outlived their usefulness after a while:

“I’ve been out of the support group environment...where people are 10 years down the road....I just wanted to find out where do I fit in. Do I fit in from being a newbie...to being 10 years down the road”, “I find the support groups out there up the whazoo but they’re all about how to deal with various illnesses that are going along at this point in time and coming out with your HIV...or whatever”.

Participants felt that there were very few opportunities for people who were HIV positive to meet and suggested that:

“I’d like there to be more opportunities for positive people to get together for social reasons”.

Some participants said that there were a few groups that provided this opportunity, but added that for most who attended, it was a social outing, and therefore was often difficult to continue to pursue friendships with people outside of the group, or meeting situation:

“I mean I meet positive people here all the time but it’s really hard for me to turn the people I meet here into friendships, social event kind of things”.

Ultimately participants found that the best way to meet people, and to fill in the time that was once filled by work, was to volunteer. Many participants found that volunteering gave them the opportunity to feel like they were contributing to society again. This participation in organizations surrounding HIV/AIDS meant more than just filling in time; for some it meant that they had to re-evaluate their choice to not get involved with people who were positive in order to

protect themselves. Eventually these participants came to accept that it was in these types of organizations, and the people that work for them, that they felt they belonged.

A feeling of belonging and trust created a foundation for the building and maintenance of friendships. While many participants experienced some challenges when it came to friends, many reported that they had great friends who were very supportive:

“I’ve been pretty sick in the past so...and then I’ve gone through a couple of years or 3 or 4 years where I’ve been pretty well...and then, now I’m not well again so people are kind of rallying around me so I feel like I’ve got some good support”, “They’re still there. I mean sometimes I have to kick them out”.

Friends who had a positive attitude and who were active in participants’ lives also encouraged participants to maintain their healthy status. They talked about being inspired to stay healthy not only for themselves, but for others in their lives. They said that it was much easier to hide when there was no one who had access to the everyday challenges of their world. When others were also invested in their health, they then coped and could focus on others’ investment to help get them through:

“there was a sense when you’re by yourself like you say, it’s easier to make yourself miserable and hide the fact that you’re not eating and sleeping properly whereas when you have somebody in your life then there’s a sense of I want to be strong and healthy not only for me, but for my relationship as well”.

Healthcare professionals

The final categories of relationships discussed by participants were those with healthcare professionals. As illustrated through the discussion of relationships, participants spent some time evaluating and re-evaluating who they gave access to and how much. The discussion of control in regard to the medical profession varied quite a bit. Some participants stated they were in control: *“I decide what pills go in my mouth”*, whereas others felt that this was the one

relationship where control was tenuous. Participants talked about being stripped of control as they found themselves needing to give the medical profession “full access” in order to be assessed and treated for the disease, symptoms and side effects. In this situation, what was important to them was ‘the need’ to relinquish control and provide access rather than ‘the want or desire’ to:

“I’ve been in emerg and you have that little curtain between you and the person next door and then they bring in the other doctor, this is Mr. So and So, he’s HIV+, has this and that..”

Now anyone within hearing range of their cubicle has the knowledge as to why they are there and what they are being treated for.

The consequences of such knowledge confirmed the fear:

“...and I had nurses come in and it’s like...poking me six times because they were shaking so bad to try to take a blood sample...and it was just humiliating...anything that happened to you it was suddenly related to HIV...”

“and it was like I just didn’t feel like a person anymore, anytime I had to have medical attention...and I’ve never been sick from any HIV-related problems ever.”

Other medical relationship issues also had something to do with control, but focused on control of medical information, medications and treatments rather than with control of access to participant’s everyday world. Participants experienced their relationships with doctors individually depending on their stage in the illness and personal circumstances. Some participants talked about taking control over their illness by researching treatments and bringing this information to their doctor. Others talked about placing trust in their physicians as they had decided to leave the prescribing choices and decision making up to them.

Finding a Way to be Productive

Loss of paid employment became an issue for many participants. Along with loss of employment came financial difficulties. This meant for most the need for reliance on income support. Some saw that relying on such income support gave them a chance to stabilize their symptoms, and gave them time to learn how to incorporate other symptoms into their daily lives. While income support was seen by some as a chance to “check out for a while and focus” on themselves, for others such support felt like a prison sentence:

“And even if we stayed on disability our income doesn’t really increase at the rate of the cost of living increases so we’re progressively becoming poorer and poorer, and I find that really frustrating. My working friends, whether they’re positive or negative, I mean even the positive ones who sucked it up and stayed in the workforce, their income has increased over the last 10 or 15 years. I feel like I’m just socially not able to do all the things that they’re able to do because I don’t have the money and so as much as my friendships aren’t based on income, at the same time if you can’t do the things that they’re doing you fall out of the friendship loop pretty quick.”

Participants were very vocal about the fact that living in poverty was perhaps one of the biggest issues for PHAs:

“Like those are huge issues, poverty issues...it’s actually the initial reason why I went to join the study...was for the \$25...honestly...because poverty I think is the number one issue PHAs are dealing with and we need people to listen to that because...I mean there is the fear that you can’t go back to work because of the fear I need this money for my drugs, rent and all this stuff...”

And so the experience of poverty had its own consequences:

“I find that makes me feel sub human...I mean I went through a move just recently...seeing a mattress in the garbage and having to drag it home because I have no furniture...I don’t feel human...I feel less than human...like I feel like I’m a scavenger, crawling around on the ground. That’s what you get reduced to.”

Participants expressed their fears of living into old age and in the state that they had been living in:

“I feel like I’m a bum off the street sometimes, and I never had to live like that in my life...so it’s been a huge adjustment for me to find myself after all these years. I thought

I would be somewhere now and have a half decent life by this time because I turned 49 this year. I thought my life would be different and to think that I might have another 20 years of scraping by..."

In addition to living with the ups and downs and stress of the disease, participants also made it known that having to live a life of poverty impacted on their ability to cope, and took away the little energy reserves that they had:

"Trying to have control is not having income and money and food as I was saying before...that kind of control, that is very difficult to maintain. When you're on social services in this province it isn't, it isn't making you a very good living. People find other ways to supplement their income or food bank or wherever you can. But that...I mean if we had enough to maintain a quality of life through income would probably make things easier. If I didn't have to worry about food in the cupboard and bills getting paid and having enough pot to smoke, I think I wouldn't worry about whether or not I was going to get sick next week".

It is clear that living in poverty, as described by the participants, impacted on their sense of self as well as their sense of value and place in the world. While participants held hope of returning to the paid workforce in order to relieve themselves of the economic constraints of government income, in the next section we learn of the challenges and barriers that prevented them from doing so.

Work

Paid work plays an integral part of almost everyone's everyday world. A career fulfills many needs including personal achievement and satisfaction, economic needs and societal needs. Because paid work is such an integral part of our North American culture, in many ways it has come to be a defining part of self, and measurement and recognition of normalcy. Some participants in this study continued to be employed, while the majority of them did not. Because paid work was such a defining factor in their lives, participants felt that:

“being HIV you are a nobody now because you can’t go to work because what employer is going to want to hire you when you can only maybe work 30 hours a week if you’re in that able level...or a day where I can only work 3 hours today”.

Whether participants continued to work or not, they all were able to talk about issues surrounding a work identity, income, and the unknown aspects of the future.

Those that continued their employment identified their fears and challenges surrounding work somewhat differently than those who were not employed. Working participants talked about their fears of having to give up paid work one day, which for them would mean giving up a large part of their identity. The motivation to continue working for them was that it provided a distraction from HIV. These participants felt that to lose that would be difficult, as they would not know how to fill in the time. For some, however, the motivation to continue working was purely practical in that they needed to continue to support themselves and their medical needs, so they:

“work to pay your bills...you’re sick inside but yet you got to be on the outside looking like you’re well and physical and capable of doing it and meanwhile it’s very stressful... And when you have a bad day and you got to be up at 6:00 in the morning...”

The participants who continued to work identified a number of challenges to their continuation including management of their work identity, fears of the future, and the potential for dramatic change in their health status. All of the participants who were still working explained that they were very careful at work, and only shared information regarding their HIV status to select individuals:

“And not everybody knows about my status...with whom I work with...or whatnot...They don’t always need to know...”

This sometimes became a challenge for those participants who were symptomatic, or were on medications:

“I’ve done it for years...working and having...like a problem...like I would need to go to the bathroom to take my pills ‘cause I was working then and the public and everything.”

This group also discussed their fears of the future and the potential of not being able to maintain their lifestyle due to loss of income. But the most distressing part of the future for these folks was the fear of not being on a drug plan and therefore not being able to afford their medications:

“it’s always in the back of my mind will I be covered as long as I’m here. You know what I mean? There’s an insecurity that there’s no way you can deny it.”

The potential for the loss of resources for medication costs is one that all the participants could relate to, and those who were presently on medication seemed to feel that reality just a little bit more, acknowledging that they knew where they had been, and they did not want to go back.

For those who were no longer working, there was a lot of reflection on their past working life, especially in relation to losses and choices when it came to work. Many of the participants talked about having to make the choice of working or being healthy:

“you can’t afford to take that chance because ultimately your health is more important than just making money. I gave up all that. It’s survival, that’s all there is to it. It’s just pure survival.”

The choice, or need to leave work for many came down to a choiceless-choice:

“I literally had to decide at one point to do something about it because if I didn’t I was going to die, and that just wasn’t an over-dramatization at all. That was just a certain fact.”

Leaving work, therefore, meant recognition of the unmanageability of symptoms and side effects of medications, and an attempt to regain control. The need to leave work in order to regain some sort of manageable health status meant that these participants had to give up a part of how they defined self, their work identity:

“my sense of self-worth is really wrapped around being employed and being part of the workforce so I find that challenging.”

This journey for better management of life with HIV was an ongoing one, but as they experienced some sort of stability they could not seem to help but think about the life they once had:

“I would love to have the energy I had back before I was diagnosed”.

When participants talked about the need and want to return to work these ideals were outweighed by the risks and challenges they identified. The risks were defined by potential losses and the challenges by barriers that they felt were insurmountable. The participants identified two distinct and defining risks that influenced their decision regarding going back to work: the risk of getting sick, and the risk of loss of benefits and income from either private or government sources. The challenges identified by participants included the societal expectations of workers and lack of suitable positions for people who needed flexibility and understanding built into their work role.

Because this group of participants had to leave work in order to better manage and maintain their health status, they were very open about their fears of relapse and the unknown effects returning to work might have had on their health:

“the last time I went back to work...it just caused a total collapse of my cocktail...I mean I want to go back to work in some ways but in other ways it’s like what happens if that happens all over again”.

Despite these very real fears of a relapse, this did not seem to be the overall deciding factor in terms of returning to the workforce. The most prevalent fear of returning to work was that if something did happen and they were not able to continue to work, then they would have given up the security of their current source of income, whether it be government or private disability funding.

Participants who were on disability pensions from their employers feared that:

“there was a risk that if I did go back to work, they could cut me off 2 months down the road saying, you’re not doing your job right, goodbye, and then I’d really be screwed”.

The fear of potential loopholes in government disability benefits also kept people dependent:

“it was difficult enough to get onto disability benefits and then even more difficult to get additional benefits by tweaking legislation and using it to get more funds. If I went back to work they would close my life and I would lose all of that and the way legislation is now you’d never get it back”.

The fear of losing government income and medication coverage was unquestionably the greatest risk impacting participant’s decisions regarding work:

“there is the fear that you can’t go back to work because of the fear I need this money for my drugs, rent and all this stuff...but if we went back to work...we might feel better in health...we may not need the drugs”.

All participants on government income came to the conclusion that they were not willing to take the risk of going back to work, so that they would be able to maintain their benefits.

These participants felt that the government needs to *“get the...red tape regulation changed”*. It was clear that if there were some kind of a guarantee that if they tried to work and had a relapse or were not able to work full time, that the government would reinstate benefits. Then they would be more willing to return to work:

“I feel healthy enough that...I have an opportunity to take a full-time job but I’m scared, I’m always scared something is going to happen. It’s going to take me so long to get back on disability that you know it’s frustrating. And yes you do want to work and you think...ok this is going to be great...I can have a nice full-time job but I’m too scared that something is going to happen. My body’s already given out on me now in the last little while so it’s like should I or shouldn’t I, and I’m going no”.

The Conundrum: All or nothing at all

In the above discussion regarding work, there seemed to be an all or nothing attitude. From this perspective, you either worked, or you did not; there was no consideration of the number of hours worked or talk about full or part time options. It ultimately became clear that

this all or nothing attitude was not because there was a lack of desire to work, but rather it was a result of the stringent structure of our workforce:

“I’m not able to do everything like a normal person does...some days I’m fine, I can do a lot, but there’s other days I just curl up in bed and stay there for the whole day”.

The participants acknowledged that there was no place for someone who could not be consistent.

The unpredictability of the illness on a daily basis, according to the participants, made it impossible for them to return to work even though they had periods of time when they felt that they were healthy enough to work:

“I’ve often thought about I don’t want to be retired really and my health is often good enough that I feel like I could work but I don’t know if I could work consistently”.

It was clear that participants who felt healthy enough to work had the desire but not an accessible work structure to support them.

Returning to work might be partially about making money and getting themselves out of a life of poverty, but there seemed to be more value placed on the emotional impact of working or, more clearly, not working:

“there are emotional risks attached to that of not working, to not be productive, and to not feel you’re doing something useful with your life”.

There was a lot of discussion around forced retirement, or having to retire too young:

“It just hit me like a ton of bricks and I thought I’m already retired and I have another 25 years to go before I officially retire and I found that to be just overwhelming and the thought that today was going to be exactly the same as 25 years from today...it sent me into a huge depression. It took me awhile to get out of it. And I attribute it to the fact that you know I’m living a retired person’s life and I don’t like it”.

Other participants reiterated that being retired at such a young age made thoughts of the future challenging and bleak:

“we don’t have milestones...I don’t have milestones and I find that difficult to deal with because if you don’t have those milestones to pull you through your time...then every day

does start to look like the same one...one after the other. So I find that that's what I'm missing is milestones and goals”.

The management of illness whether on an hour-to-hour, day-to-day, or month-to-month basis was really what returning to work came down to. In order to manage illness, participants needed to be able to afford and take medications, be able to achieve and maintain basic standards of living, including a roof over their heads, food on the table, and the management of symptoms and side effects in their everyday life. Participants felt that there was no available space for them in the workforce of today that would allow them to manage illness and contribute to society, and at the same time feel secure that if they suffered a relapse or episode they would be supported without having to “*fight to get back on disability*”. A few participants created their own space in the workforce, working under the table when their health allowed:

“when my body...I hear my body ok, I have to take a nap today. Today is not going to be a day where I can work 16 hours and do it. I mean today I can only get 3 hours done. I'm aware of that. I listen to that. That's worked for me and I haven't gotten sick again, luckily. But I guess for me that's how it works for me”.

SUMMARY

When a disease is terminal, the experiences of major ups and downs seem to fit the dramatic events that herald the progression of an illness' trajectory. Re-experiencing that illness' change from an imminently fatal condition to a longer lasting fatal condition seemed to require or result in a redefinition of the meaning of those peaks and valleys and while they may have occupied significant moments in time, they eventually appeared to become shadows that accompanied the experiences of everyday living.

Our focus group questions and probes were designed to guide participants to reflect on their episodes of illness and symptoms in a more defined way, but what they revealed in their

discussions and through their stories was something quite different. Rather than selected or a series of dramatic episodic events, there was instead a continuing vigilance of attending to signals, anticipated and actual, that implied to them, deterioration and/or debilitation. The everyday ebb and flow of one participant's illness experience was described as "feeling good, feeling like crap, feeling good". While some participants did talk about major episodes or events in the experience of their illness, we were most overwhelmed by the day to day struggle that they talked about and the ongoing challenge to pursue living in the face of uncertainty of what the next moment, next day or next year would bring:

"so you don't know what's going to happen or when its going to happen...HIV is the driver as far as the out of control elevator because you don't know what floor you're going to land on and sometimes you'll land on the floor that you've pressed the button for..."

At the same time we learned from others that the ups and downs of their everyday life were experienced as "ripples or bumps":

"I'm fine...other than a roller coaster...it's more like you go down and then up and then you sail on one level, and you go down again...but you come back up and once again it's smooth...it's not like woo, woo all over the place..."

In posing the question of "ups and downs", we assumed that participants experienced and measured "ups" but we discovered that most of the participants did not use this term. As one participant said:

"When is it up?...it always is...I mean ever since I was diagnosed it's always gone the one way...I mean really in all seriousness, your up is that it stays on a plateau..."

...and another in response to the question said:

"..and I have to really stop and reflect on times that I have these ups and downs.. as you ask questions...because I don't think about them as being ups or downs...I just look at it as being part of life because no matter what, being HIV positive or not, we are all going to have the roller coaster of life..."

Whereas variability was experienced by some participants, others emphasized the unpredictability of the illness:

"Like when you think you are going to fart and you have explosive diarrhoea...or you don't know if you should sit on the toilet or puke in the sink."

The impact of the unpredictability on the participants' life was generally to withdraw:

"I can't go anywhere or do anything"

or:

"gotta stay inside just because you can't go out because you're scared..."

For another participant:

"When you're feeling like that, you don't want to eat, you don't want to deal with people, you don't want to deal with meals"

The uncertain course of HIV and its treatment threatened to limit the participants' freedom and cloud their future planning:

"it means once you experience something then there...like if you get involved in something and then you get ill and you can't see it through, then you're more hesitant to get involved again just in case you get ill and have to stop again..."

In response to this challenge, they had to educate themselves, be patient, accept their illness, talk to others, know their limits or as one participant said:

"...it's adapt or perish...you have to keep going forward...you have to keep going forward because if you stand still, you know...you'll be torn to pieces...you have to go forward..."

Crossing all the themes of these discussions was the struggle for balance against the seeming chaos of their circumstances:

"...yeah...I have been living day to day for so long...and I can't stand living day to day any more...I want...I need some sense of direction...some sense of overall balance against the chaos that keeps life fun...the right kind of chaos..."

Another participant described...

"it changes every aspect of who I am...I mean my every....., everything that I say...everything I experience is on a different flavour and in some ways...I do grow stronger and in other ways I grow weaker...it's sort of like you gain one thing and you lose another...and it's finding...I think for me...it's finding the balance between that..."

And so, out of lives that were "problem saturated" with little life beyond their disease (Robinson, 1993), they summoned their reserves and persevered in a reorientation of their stories:

"it is not a matter of obsessive control over the details...it's a matter of having the big picture...and the right amount of the right kind of, the kind of chaos and unpredictability that makes life rich and interesting.. while trying to deal with the best you can with the frightening bit that can open up at any moment...the ability to sort of take, you know, the gifts of life...whether they're thrown at you and try to side step the dangers...and to know...you know you've got some sort of purpose and head towards it..."

These participants articulated the struggle and the different transitions that were accomplished, most clearly:

"...well control, you see, depends on personality...I mean there are some personalities that are more controlling than others naturally...there are some people that are quiet and more reserved and actually take a different approach...there are people who are sometimes depressed and there are people who never had a day of depression...some of that is...each one of us is made a little differently...but one thing is for certain...we all do have some common threads...all...yeah... just live day by day and hope it gets better before it gets worse..."

As Charmaz (1995) suggests, through their struggles, ill people paradoxically grow stronger in self and they "adapt to impairment. They suffer bodily losses but gain themselves". Their journey leads to another level of self-awareness and their position relative to their situation and their place with others and at this point they may even find themselves giving "solace and comfort to the healthy".

As one participant concluded:

"I know my final thoughts are...just don't let it get to you up here... there's still just so much hope for even a better future than what we even have now...or what we've had

for...well for anybody who's been infected for at least 10 years...I mean if you start taking a look at what it was like 10years ago and now...I mean there's an awful lot of hope and don't give up...maybe you'll be a little nervous about the therapies and stuff like that...but don't give up on yourself.."

CONCLUSION

Uncertainty seemed to be a central feature of the experiences reported by these participants in living with the complexity of their illness, its unpredictable and ambiguous trajectory and the complex and unproven efficacy and safety of treatments (Mishel, 1990). In telling their stories they revealed the many ways they coped with the dangers and threats they experienced in living with this disease. The challenge for most was to attempt to find some balance between their personal resources and their environmental supports, when for many, personal resources were limited (e.g. energy, depression) and environmental supports (e.g. financial, work, family, friends) were absent or minimal. Nonetheless, they faced the challenges and managed the complex interplay of the uncertainty with their emotional distress by seeking some coherence and meaning to their lives.

The analysis focused on the day to day experiences of living with HIV/AIDS and as the analysis suggests PHAs are still confronting many of the psychosocial challenges as in the pre HAART era, although in different guises. While AIDS is being reclassified as a “chronic illness”, we need to continue to value and build upon what we have learned about people’s everyday efforts to cope with the illness, since it can be seen, through this analysis, that many of the same issues remain relevant as the epidemic continues.

LIMITATIONS

Caution must be exercised in the interpretation of this study's findings. First, the sample was drawn from small groups of volunteering PHAs in selected areas across Canada, who are by no means representative of the PHA population. Participants came from ASOs and this bias may have influenced the nature of their characteristics and life experiences as well as their willingness to participate.

Neither the transcripts nor the interpretive analysis were reviewed by the participants for accuracy. While this decision was reasonable, as a way to ensure the protection of their anonymity and their belief in that protection, the decision could reduce confidence in the validity of the interpretation.

How the authors created the stories of the participants should reflect but not necessarily reproduce the participants' stories (Charmaz, 1990). Our conclusions are an attempt to offer concepts that preserved the context of the story, and the person's character within it. To this end, our active codes and subsequent categories attempted to represent the images of the reported experiences (Denzin & Lincoln, 2000). As noted by Glaser and Strauss (1967, p23) "in discovering theory, one generates conceptual categories or their properties from evidence; then the evidence from the category is used to illustrate the concept". The quotes that appear in this paper were selected examples of the responses provided by the participants that were judged by the authors to fit the various conceptual categories which emerged during data analysis.

When using qualitative methods, it can be seen that the researchers brought the general perspectives of their disciplines, their own philosophical, theoretical and methodological tendencies, their particular research interests and their own life experiences. Hence the questions that were developed, the data collection methods and what issues and focus they saw within the

data, obviously shaped the analysis. Thus the decisions that we made throughout the research process have shaped this product.

IMPLICATIONS FOR FUTURE RESEARCH

As this analysis implies, it was not only the unpredictable episodes of illness that challenged HIV/AIDS sufferers, but also it was the management of the multi-layered uncertainty (personal, social and medical sources) through adjustments in identity, relationships, knowledge and physical and psychological well being.

What was needed was a fit between the needs and resources of the person and the demands and resources of the environment. Proactive individualized multidisciplinary interventions targeted at the individual (treat depression, vocational training) and/or the environment (flexible work hours, supportive housing) could be developed to identify and strengthen available resources.

ACKNOWLEDGEMENTS

Our sincere thanks to all the participants who generously offered their time and shared their personal and moving stories. In addition, we are grateful to the Project Co-ordinator, Kelly O'Brien, the organizer and facilitator of the focus groups, Kate Reeve, along with the various co-facilitators who guided the groups and for the co-operation of all the personnel in the ASOs who helped make the study happen. Many thanks to the Advisory Committee members, Tom McAulay, Peter Williams, Patty Solomon, Kate Reeve, Vivia McCalla, Peggy Proctor, Kelly O'Brien and Elisse Zack for their investment in this project and their commitment to its completion. Finally, many thanks to Leah Heikoop for her skill in producing the final document.

REFERENCES

- Babbie, E. R. (1995). *The practice of social research*. 7th Edition. Belmont, California: Wadsworth.
- Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russel, J. A. and Haas, S. M. (1999). In an important way I did die: uncertainty and revival in persons living with HIV and AIDS. *AIDS Care*, 11(2):201-219.
- Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W. & Russel, J. A. (2000). Communication in the management of Uncertainty: The Case of Persons Living with HIV or AIDS. *Communication Monographs*, 67(1): 63-84.
- Bullers, A. (2001). Living with AIDS---20 Years later. *FDA Consumer*, December.
- Calnan, M. (1987). *Health and Illness: The Lay perspective*. Tavistock, London, UK.
- Charmaz, K. (2002). The self as habit: The Reconstruction of Self in Chronic Illness. *The Occupational Therapy Journal of Research*, Volume 22, Supplement: 315-415.
- Charmaz, K. (1995). The Body, Identity and Self: Adapting to Impairment. *The Sociological Quarterly*, 36(4):657-680.
- Charmaz, K. (1990). "Discovering" Chronic Illness: Using Grounded Theory. *Social Science Medicine*, 30(11), 1990: 1161-1172.
- Conrad, P. (1990). Qualitative Research on chronic illness: A commentary on Method and Conceptual development. *Social science and Medicine*, 30(11):1257-1263.
- Corbin, J. and Strauss, A. (1986). Managing chronic illness at home: three lines of work. *Qualit Sociol* 8: 224-247.
- CWGHR (2002). *Looking Beyond the Silos*.
- Denzin, N. and Lincoln, Y. (Eds). (2000). *Handbook of Qualitative Research*. 2nd Edition. Sage Publications: Thousand Oaks, California.
- Gallo, R. (1996). AIDS as a clinically curable disease: the growing optimism. *AIDS Patient Care and STDs*. 10:7-9.
- Glaser, B. G. and Strauss, A. L. (1967). *The discovery of grounded theory: strategies for qualitative research*. Chicago: Aldine.
- Goldman, R. (2000). Being Chronically Ill. *Acquired Immune Deficiency Syndromes*, 23(4): 295-301

- Ferrier, S. E. and Lavis, J. N. (2003). With health comes work? People living with HIV/AIDS considering returning to work. *AIDS Care*, 15(3): 423-435.
- Karp, D. (1996). *Speaking of Sadness: Depression, Disconnection and the Meaning of Illness*. New York: Oxford Press. (Reviewed by Kathy Charmaz).
- Kitzinger, J. (1994). Focus Groups: method or madness? In M Boulton (Ed.) *Challenge and Innovation: methodological advances in social research in HIV/AIDS*. Bristol, PA: Taylor and Frances:159-175.
- Krueger, R. (1998). *Developing Questions for Focus Groups: Focus Group Kit 3*. Sage Publications, Inc., London, UK.
- Krueger, R. (1998). *Moderating Focus Groups: Focus Group Kit 4*. Sage Publications, Inc., London, UK.
- Lewis, J. (1999). Status Passages: The Experience of HIV-Positive Gay Men. *Journal of Homosexuality*, 37(3): 87-115.
- McGuire, M. and Kantor, D. (1987). Belief systems and illness experiences: the case of non-medical healing groups. In *The Experience and Management of Chronic Illness (Research in the Sociology of Health Care, Volume 6)*. JAI Press, Greenwich CT.
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship*, 22: 256-262.
- Moatti, J. and Souteyrand, Y. (2000). Editorial: HIV/AIDS social and behavioural research: past advances and thoughts about the future. *Social Science and Medicine* 50:1519-1532.
- Morgan, D. (1998). *Planning Focus Groups: Focus Group Kit 2*, Sage Publications Inc. London, UK.
- O'Connell, P and Levinson S. (1991). Experience with Rehabilitation in the Acquired Immunodeficiency Syndrome. *American Journal of Physical Medicine and Rehabilitation*: 195-2000.
- Pierret, J. (2000). Everyday life with HIV/AIDS: surveys in the social sciences. *Social science and Medicine*, 50:1589-1598.
- Proctor, P. *Looking Beyond the Silo: Disability Issues on HIV and Other Life-long Episodic Conditions, Final Report to the Canadian Working Group on HIV and Rehabilitation (CWGHR), March, 2002.*
- Register, C. (1987). *Living with chronic illness: Days of Patience and Passion*. Free Press, New York.

- Robinson, C. (1993). Managing Life with a chronic condition: The story of normalization. *Qualitative Health Research*, Volume 3(1): 6-28.
- Scandlyn, J. (2000). When AIDS became a chronic disease. *Western Journal of Medicine*, 72: 130-133.
- Siegal, K. and Knauss B. (1991). Living with HIV-infection: Adaptive tasks of seropositive gay men. *Journal of Health and Social Behaviour*, 32(3):17-32
- Siegal, K. & Lekas, H. (2002). AIDS as a Chronic Illness: Psychological implications. *AIDS*, 16(4): 569-576.
- Stillman, F. (1992). Focus Group Research: an overview .In M Becker (Ed.) *Health Behaviour research in minority populations*, Washington DC: USDHHS:168-175.
- Strauss, A., Corbin J, Fegerhaugh S, Glaser B, Maines D, Suczek B and Wienes C. (1984). *Chronic Illness and the Quality of Life*, 2nd edn. Mosby, St Louis, MD.
- Tiamson, M. (2002). Challenges in the Management of the HIV Patient in the Third Decade of AIDS. *Psychiatric Quarterly*, 73(1):51-58.

Epilogue: Reflections of the Advisory Committee

The purpose of this section is to provide the reader with some overall reflections of the advisory committee on the how this report from “Phase II“ of the Episodic Disability Project fits with the report from Phase I (*Looking Beyond the Silo*). It also includes some thoughts on future implications for rehabilitation programs and policies pertaining to episodic illness in the context of HIV.

Definition of “Episodic”:

- One of the themes that emerged from the key informant interviews held in Phase I of this project (*Looking Beyond the Silo*) was the need to establish relevant definitions pertaining to lifelong and episodic illness. We had hoped that results of Phase II might help to establish a definition of “episodic” to help us better conceptualize and describe the unpredictable and roller-coaster-like experience of living with HIV. Many factors contribute to the “episodic” nature of living with HIV beyond the biological impact of the virus, its effect on the immune system, and the resulting illnesses. For example: anticipating new side effects with every change in treatment, possible changes in employment, adjusting to new living arrangements with changes in income and health status, and coping with changing support systems as friends die and/or friends and family react to a person’s vulnerable health and periods of illness and wellness over time. It did not seem possible to create a new definition of “episodic” disability that would capture the complexities of what these participants shared in their stories.

- Some participants seemed to have a sense that HIV is supposed to be, or will become, episodic. So while they themselves may not have experienced a major episode, or series of episodes, the impending threat of HIV taking control and their not knowing what will happen has a significant impact on how life is lived and how it is perceived and described. This highlights the ongoing unpredictability associated with the illness, the ongoing uncertainty of the potential for an episode to arise and the uncertainty of how one will cope with an episode if and when one arises.

Comparing Results of Phase I and II:

- One of the objectives of the Phase I *Looking Beyond the Silo* project was to conduct key informant interviews with representatives of various national organizations working on other lifelong and episodic illnesses to identify similar disability and rehabilitation issues. A few of these themes that emerged from the Phase I key informant interviews also emerged from the focus group discussions of persons living with HIV in Phase II. For example, workplace issues and income security were two themes that emerged from the Phase I key informant interviews. Similarly, issues surrounding work and finding a way to be productive were themes that emerged from the Phase II focus group discussions with persons living with HIV. This highlights areas of importance related to workplace and income support issues for persons living with HIV, as well as other lifelong and episodic illnesses and helps to identify areas in which to focus future policy and program development.

Implications for Future Work on Rehabilitation Policies and Programs:

- Beyond what makes HIV unique, the committee believes that the impact of living with HIV has much in common with other lifelong, episodic conditions and that alliances would be effective in facilitating change at the policy level. It is the hope of this committee that this report will facilitate future partnerships and further research to facilitate change that provides a better quality of life to people living with lifelong, episodic illness. This may require a redefinition of terms and/or the creation of new terms to accurately reflect the experience of people living with episodic disabilities / conditions so that points of common experiences may be determined based on their own experiences and priorities.
- As stated above, it was intended that this report might provide a clear definition and understanding of the term “episodic”, reflecting the experience of living with HIV. While it may not have done that entirely, it has provided insight and new understanding that suggests further research in this area. For example, more work could be done to focus on the cumulative impact of living with an episodic illness. Is there an “erosion effect” over time? Do people living with an episodic illness redefine or reframe ‘episodic’ from the dramatic to a more common, manageable experience of ripples and bumps as a coping mechanism?
- The results from Phase I and II of the Episodic Disability Project have provided a comprehensive knowledge base. This information will serve as a springboard from which CWGHR will launch Phase III of the Project. Phase III will involve moving from research into community development and knowledge transfer with the initial development of a network of organizations working on episodic disabilities or conditions.

The goal will be to embark on an action plan to promote changes to rehabilitation programs and policies to better address the needs of persons living with HIV and other lifelong and episodic illnesses.

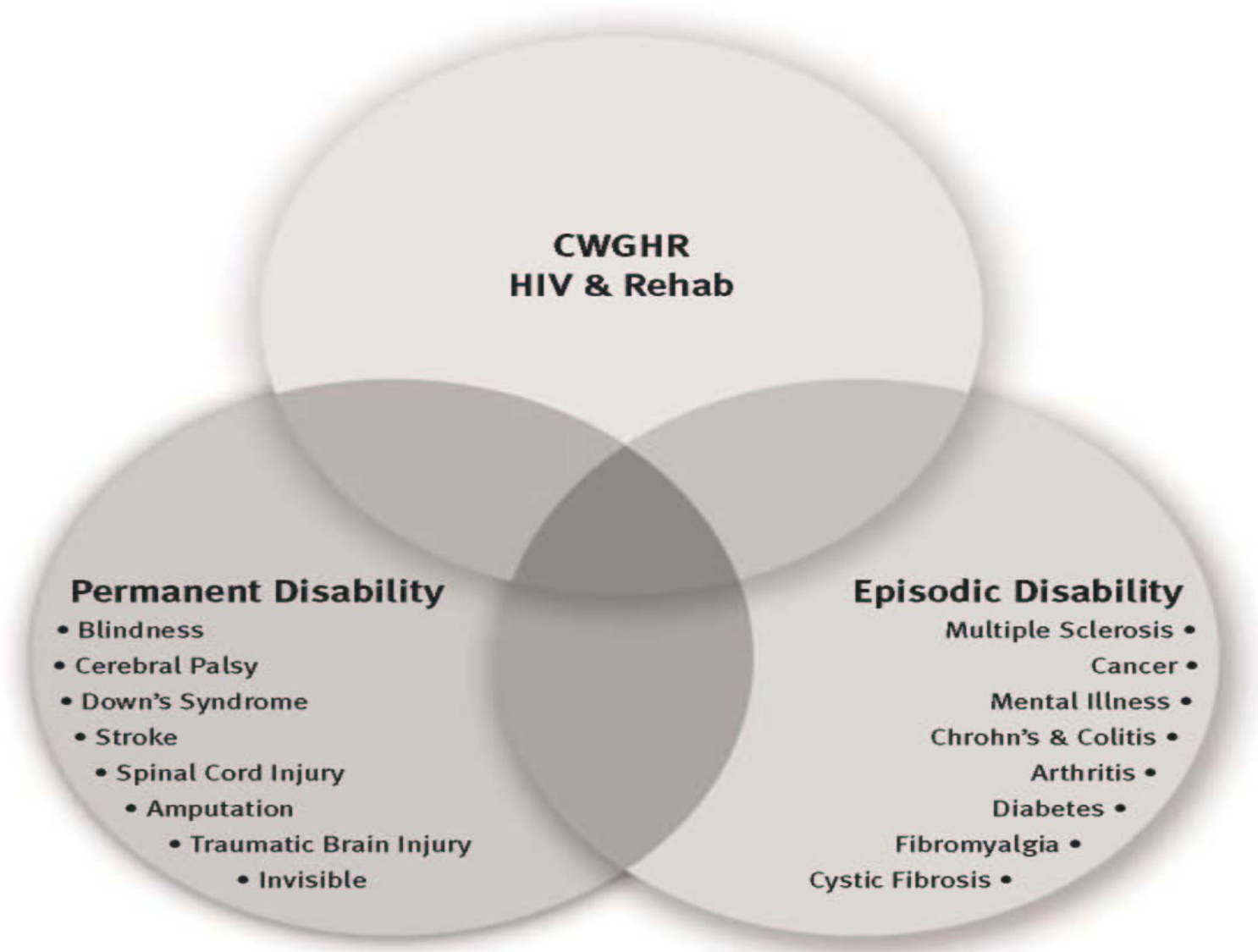
CWGHR will incorporate this research along with other project findings into our educational materials and workshops to enhance our existing resources on rehabilitation in the context of HIV. It is through this ongoing work that CWGHR will continue to promote excellence in rehabilitation as an integral component of the care, treatment and support of people living with HIV.

APPENDICES

Appendix A

Conceptual Model of Cross Disability Issues

Appendix A
Conceptual Model of Cross Disability Issues



Appendix B
Information Sheet

You are being invited to participate in a focus group.

Who is doing the focus group?

The Canadian Working Group on HIV and Rehabilitation (CWGHR) and 2 researchers from the Community-Linked Evaluation AIDS Resource (CLEAR) Unit, McMaster University, Hamilton. CWGHR is a national, autonomous, multi-disciplinary working group with the mission to enhance the quality of life for Canadians living with HIV disease by facilitating the development, awareness and access to rehabilitation services.

Why are we doing the focus group?

While people with HIV/AIDS are living longer, they are living with the unpredictable and fluctuating nature of the illness. As a result, we are trying to learn from you the reality of living with HIV/AIDS in relation to the uncertain, unpredictable and fluctuating nature of this disease and the “roller-coaster” like trajectory of that reality; those episodes of feeling ill, then better, those peaks and valleys, ups and downs that occur. A better understanding of these experiences will lead to the development of relevant HIV rehabilitation programs and policies to ultimately better meet the needs of persons living with HIV/AIDS.

What are we asking participants to do?

You are invited to take part in a 1 – 1 ½ hour focus discussion group with 5-8 PHAs. This is not a counselling group, but rather is a group to discuss issues regarding your experiences with an episodic illness. You will be asked a series of questions to discuss the experiences that you have living with HIV. After the focus group discussion, you will be asked to complete a short questionnaire based on your personal characteristics. An honorarium of \$25.00 will be provided to thank you for your participation.

How will the information be used?

The focus group discussion will be later converted into a written format from the audiotape. The notes will then be analyzed for common themes that emerge related to the experience of living with a lifelong episodic illness.

How is my privacy protected?

Your participation in the focus group is voluntary. The focus group will be audiotaped. The tapes will be transcribed at McMaster and any identifying information (e.g. first name) will be removed. The tapes will be destroyed after transcription.

How can I participate?

If you are interested in learning more about the study or if you wish to participate, please call Kate Reeve at CWGHR in Toronto, 416-324-4183.

A summary of the results will be available to study participants at the completion of the study through the local AIDS organization.

Appendix C
Consent Form

Appendix C

**Unpredictable Episodes of Illness in the Experiences of People
Living with HIV/AIDS
Consent Form**



The Canadian Working Group on HIV and Rehabilitation (CWGHR) is doing a study about the day-to-day experiences of people living with AIDS. We would like to meet with you to try to understand your experience over time with your illness. We are particularly interested in understanding those episodes of feeling ill, then better, those peaks and valleys, ups and downs that occur. This is not a counselling or therapy group, but rather we want to learn from you how you cope with these episodes and manage your every day life.

I understand staff from CWGHR are going to be meeting with small groups of people living with HIV/AIDS to discuss these experiences. The group discussion will last about one and one-half hours and will be led by 2 facilitators who will assist the group to discuss the relevant issues.

I understand I am being asked to participate in one of these groups. All information that I discuss in the group is confidential. My name will not be recorded or used to identify my comments. The group discussion will be audiotaped and the tape will be subsequently transcribed by secretaries unrelated to the project. No individual will be identified in the transcription. The audiotape will be destroyed after transcription. The results of the study will be made available to CWGHR and presented in-group form (that is, no individual will be identified).

I can choose at any time to leave the group discussion. My participation in this group will not affect any services I presently receive. If I decide to withdraw from the study, I understand that the information I provided about myself will be removed from the study record.

If I have any questions about this group, or my participation, I may make a collect call to Kate Reeve at CWGHR in Toronto, 416-324-4183.

The study will take about 6 months to complete. If I am interested in receiving the results of the study, I can call the above phone number.

Yes, I understand the purpose of the focus group and the expectations for my participation.

Yes, I agree to participate in this tape-recorded discussion group.

Signature _____

Print Name _____

City of Residence _____

Witness Signature _____

Witness (printed name) _____

I will receive a signed copy of this form.

Appendix D

Interview Guide

Appendix D
Unpredictable Episodes of Illness in the Experiences of People Living with HIV/AIDS
Interview Guide

With earlier detection and effective drug treatments, more and more people infected with HIV are living a long time with their disease. We are meeting with you to try to understand your experience overtime with HIV/AIDS in relation to the uncertain, unpredictable and fluctuating nature of this disease and the “roller-coaster” like course of that reality. We are particularly interested in understanding those peaks and valleys, ups and downs, that occur, those episodes of feeling ill, then better. We would like you to discuss with us the impact these episodes of feeling ill then better have on your life.

Describe your experiences that made you think that you were right for this discussion group (i.e. that you could relate to what we were trying to understand about your illness).

Consider how these peaks and valleys impact on all aspects of your life. For example:

- work life
- finances
- relationship with family of origin, partners and outlook on life

Probes:

- How has living with the “roller-coaster” affected your outlook on life?
- Has the anticipation of a new/impending critical event affected your outlook on life?
- If you have had multiple ups and downs with your illness, how has this impacted the way in which you anticipate a new critical event? How has this affected your outlook on life?
- How do these ups and downs relate to changes in your perspective on life?

Let’s talk about the unpredictability of the disease.

Probes:

- How do you deal with the uncertainty when your symptoms are quiet?...present?
- When you don’t know how long you will respond positively to the treatments, how do you cope with that uncertainty?
- Some PHAs have told us that they can now plan ahead. Do you have any comments to make about looking forward, planning ahead, even dreaming about the future?

It may be difficult when there are ups and downs, and many episodes of illness/wellness, that roller-coaster-like course to feel you have control over the direction of your life.

Probes:

- What is the impact on having numerous “episodes” on the way in which you cope with your illness?
- What do you think contributes to your having control over your life?
- How did your ideas about control change over time, over the course of your illness?

Do you have anything else you wish to say about living with the “roller coaster” like course of your illness?

Probe:

- Do you have any other way of describing these episodes?