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**RECRUITMENT, RETENTION  
AND DEPLOYMENT OF  
VOLUNTEERS AND STAFF PROJECT**

**Part 4**

**What are the transitional experiences  
for people who move from being a client  
to volunteer to paid worker?**

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Gina Browne, Greg Robinson**



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**EXECUTIVE SUMMARY OF RESEARCH THEME:  
RECRUITMENT, RETENTION AND TURNOVER OF VOLUNTEERS AND STAFF  
PROJECT (2000-2001)**

**Joan Crook, Robin Weir, Amiram Gafni, Gina Browne, Greg Robinson**

**BACKGROUND**

The collaborative effort that launched this ongoing research theme emerged from a survey of Ontario ASOs and an OAN Conference in which the retention, recruitment and turnover of staff and volunteers were identified as challenges to the provision of ASO services, programs and fundraising. To meet this challenge to the provision of adequate and necessary services, a search of the literature was conducted to identify the factors known to influence formal and informal organizational, personnel and client outcomes. The resulting conceptual model of labour force factors and their hypothesized relationships, served to guide the generation of researchable questions in this theme of research.

**PURPOSE**

The major question of this theme of research is to identify a) the factors that predict staff turnover rates in ASOs; b) the effects of these outcomes on client satisfaction and use of ASO resources; c) the expense (in-kind and funded) of staff and volunteer services in ASOs.

Before this question could be undertaken, a number of developmental steps were required to provide the background information to launch the ongoing project. These steps resulted in 5 projects that informed the overall model and included a) a study of workplace factors of ASOs; b) a study of the skill sets required of paid and volunteer workers in ASOs; c) a study of the estimation of the financial value of volunteer work; d) a study of the transitional steps of people who move from client to volunteer to paid worker; e) a study to identify the benefits and challenges of volunteering in ASOs.

This database will assist in the design and measurement of relevant evaluation strategies that are common to all ASOs.

**METHODS**

The overall design for the major study question is cross sectional with longitudinal follow-up of the cohort for the purpose of obtaining different types of data sets from different sources. For example, certain critical elements common to all ASOs, such as organizational roles, resources, types of client services, types of role activities, volunteer contributions, etc., were assessed in each of the participating ASOs. In addition to these standard data that were collected, each ASO's specific study question that related to the theme of recruitment, retention and turnover were developed and conducted with methods relevant to the study questions. Some

of these specific projects will be grouped into larger data sets, known as cluster evaluation, to provide information and direction for program and policy evaluation. These various levels of evaluation (individual, cluster and policy) provide multi perspective, multi level data to assess the individual and groups of projects and ultimately to test the relationships among the relevant labour force factors that influence staff behaviour, including recruitment, retention and turnover.

## **RESULTS**

Five projects were completed that provide the standard data necessary as a beginning background for subsequent individual and cluster evaluations.

Project one was a survey of the perceptions of the leadership group within six ASOs, to detail selected characteristics of these organizations that are proposed to provide the context in which work is conducted and influenced. The results indicate diversity among ASOs and some differences in organizational factors that need to be tested to determine their role in responding to change and growth.

The second project was designed to determine the skill sets required to work in an ASO by developing a comprehensive list of the skills and activities performed in the 10 participating ASOs within 22 categories of activities.

Executive Directors (or their delegates) completed the activity form by indicating the activities relevant to their own ASO, who performed the activity and the “weighting” of the importance of the activity (relevance and dispensability). One hundred and fifty-six activities were identified as performed in one or more of the ASOs with great diversity among the raters as to the weight or importance and who performed the activity (paid staff or volunteer) in their ASO. Volunteers contributed a grand total of 117,699 volunteer hours among the 10 ASOs.

The third project was designed to value the contribution of volunteer hours to the ASOs through a replacement cost approach. Executive Directors made judgements concerning how the activities performed in their ASO would be handled in the absence of a volunteer; i.e., use existing staff, hire a replacement, discontinue the service, and the overall replacement value was calculated at a value of \$1,783,641.

The fourth project was a qualitative exploration of the experiences of 18 volunteers in their transitions from clients to paid or unpaid (volunteer) work. A model documenting movement through different phases of being, belonging and becoming, developed from participants’ life stories, suggests a process of becoming participants to give meaning, value and purpose to their life.

This project examined the experiences, benefits and challenges of volunteering in an ASO. A variety of factors that led to an individual deciding to initiate a relationship with an ASO became evident. Many rewards and challenges were identified as the relationship was maintained. Useful recruitment and retention strategies were identified to nurture the ASO-volunteer relationship.

## **DISCUSSION**

The next steps for this theme of research are to complete and conduct individual projects relevant to recruitment and retention that will use relevant standard data, obtained through the above projects, to contribute to our understanding of the factors influencing retention, recruitment and turnover.

## **ACKNOWLEDGEMENTS**

This project was made possible because of the will and collaboration of many individuals and groups. It is an example of interagency planning and cooperation in which the many aspects of this project have and will provide insights into the current worklife challenges affecting the leadership and staff of Ontario ASOs.

A special thank-you to the Executive Directors of the ASOs and their Board Members and Supervisors who participated in the extensive interviews, skill set documentation, and supported the overall aspects of the study. Additional thanks to the volunteers who revealed their stories and their meanings and expanded all of our understanding about the meaning of hope.

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## **ORGANIZATION OF STUDY REPORT**

This study report is organized to:

- 1) describe the design, methods and analysis of the overall study question; i.e., predictors of turnover rates in ASOs;
- 2) describe the design, methods, analyses and results of the five specific projects that, in part, will inform the overall study question.

Reports of individual ASO projects that will be combined in relevant clusters will be added, as they are completed, to this report.

## **RESEARCH THEME**

### **RECRUITMENT, RETENTION AND DEPLOYMENT OF VOLUNTEERS AND STAFF PROJECT (2000-2001)**

**Joan Crook, Robin Weir, Amiram Gafni, Gina Browne, Greg Robinson**

#### **Introduction**

Consistent with the CLEAR Unit's mandate to assist ASOs to identify issues and questions about services in need of investigation, the CLEAR Unit conducted a survey (CLEAR Unit Annual Report, 1999) and a workshop (OAN Conference in Toronto, 2000) with the AIDS Service Organizations in Ontario. From these activities, respondents identified that one of their research needs was to explore the recruitment, retention and deployment strategies for both staff and volunteers in their respective AIDS Service Organizations. In the ASO survey, several participants identified that retaining and recruiting volunteers were challenges to the provision of adequate and necessary services for the individuals that they served and the programmes and fundraising activities they undertook.

Several reasons were identified for this evolving concern. First, advances in monitoring HIV infection have improved the prognosis for persons living with HIV/AIDS (PHAs). Until recently, service providers and PHAs expected an inexorable decline into illness and eventual death (Fee and Fox, 1992). Now, HIV is coming to be seen as a chronic but manageable infection rather than a terminal illness. Presently, the agenda for managing HIV care is in constant evolution and has placed different demands on staff and volunteers and consequently their motivation and role choices for participating in the work of ASOs.

As a result of such changes, people living with HIV/AIDS now often require service over several years rather than several months, as once was the case. As PHAs live longer, the

emphasis has become directed toward living a better quality of life. “*Traditional*” staff and volunteer services, such as buddy supports, volunteer drivers, peer counselling, support groups and hospital visitation have expanded over time to include housing assistance, foodbanks, needle exchange, counselling regarding work or family issues, information about treatment options and new treatment effects, access to complementary and alternative therapies, or nutritional counselling to name a few (Cain, 1997).

Another result of the improved prognosis for people living with HIV/AIDS is the developing opportunity and emphasis for them to remain in the workforce or re-enter the workforce. This change in work potential has resulted in a growing emphasis on rehabilitation efforts to maximize active daily living within a chronic illness and develop the necessary skills for labour force participation.

Workers in ASOs need a wide range of practice skills and need to be knowledgeable about many issues including medical treatments, and how to manage the effects of treatments, counselling about employment and related concerns, death/dying, bereavement, dealing with a culturally diverse clientele, accessing and coordinating community resources and accessing government entitlements (Cain, 1997). Not surprisingly, many workers report feeling isolated, unsupported and overwhelmed in their work (Cain, 1997).

Second, the persons infected, affected and devastated by the HIV/AIDS epidemic initially were primarily MSM and it was the gay community that rallied to provide support, and compassionate care to its own community. Though MSM continue to be most affected by the epidemic (72.8%), both in terms of the absolute number of HIV-infected persons and HIV prevalence rates, several other groups are growing in both relative and absolute importance (Remis, Major et al, 1999). For example, in Ontario persons from HIV-endemic countries

constitute a growing proportion of AIDS cases (2.3%) and mother-infant HIV transmissions. High rates of HIV infection in Intravenous Drug Users (IDUs) are reported. Persons infected by heterosexual contact represent a minority of persons infected to date (8.5%) but Remis et al. (Remis et al, 1999) report that this group is growing rapidly.

Third, issues such as burnout, grief, psychological distress and lack of rewards have all been identified as issues facing individuals who work within HIV/AIDS services provision whether these individuals be staff or volunteers (Barbour, 1994),(Bennett, Miller et al, 1995). While most studies on stress and burnout in AIDS health care have focused on the negative and difficult aspects of this work, a few other studies have considered the notion of the rewards and resilience that may buffer against stress and counter balance experiences that may lead to burnout and retention. Work life rewards such as recognition and support from management, and a positive organizational climate are factors thought to positively influence retention and reduce burnout (Breaux, 1994). Personal factors outside the work environment such as good social support, resiliency and positive mental health also are found to be contributing to job/volunteer satisfaction (Bennett et al, 1995).

Fourth, there have been changes in the motivation to “*volunteer*”. In Canada, a volunteer is most commonly defined as someone who undertakes community service work of his/her own free will, without receiving a salary in return (Street, 1994). What motivates people to volunteer has been the subject of many articles and books. People volunteer, for example, because they believe that it is important for citizens to participate in the life of their communities, to “*give something back*”, and to find a way back from their tragedy by reaching out to others. A growing group of Canadians is turning to volunteer work for yet another reason: as part of job skill development and a search for paid employment. This focus has been highlighted in the

recent provincial “*workfare*” program whereby people would receive social assistance benefits only if they participated as a volunteer doing community service work (Street, 1994). In addition, the regulation that high school students in Ontario must participate in 40 hours of community service to graduate, while potentially providing “*person volunteer hours*” places demands on the service organizations to provide meaningful work experience and training. There is no additional support for training these short-term volunteers and raises the question of what the effects of this pressure will be on the nature, duration and success of such community service efforts in ASOs?

This proposed multi-faceted study attempts to address the concerns of participating AIDS Service Organizations in Ontario relative to workforce issues that challenge the ability of ASOs to provide their services through advancing knowledge regarding factors related to the retention, recruitment and deployment of volunteers and staff.

## **Background**

Community-based AIDS Service Organizations (ASOs) in Canada, as in other Western countries, are the key players in the field of HIV/AIDS education and support services (Cain, 1997). In terms of support services, there has been a broadening of needs, both in the kinds of assistance required and in the number of people seeking help. People are being diagnosed earlier and living longer with HIV infections, and often require long-term assistance. These increasing demands and the organizational growth they encourage can make it more difficult for ASO workers to maintain user-friendly and responsive services, and they can push ASOs away from their roots as volunteer run and directed organizations (Weeks, Taylor-Laybourne et al, 1994). AIDS organizations often face many of the same difficulties of larger and more established

service providers. As a result, workers in ASOs must then adapt to changes in the epidemic, their organization and their work environment (Cain, 1993).

The way in which services are organized and delivered can have significant effects on the nature of the demands experienced by staff (Barbour, 1994). In general, the literature sheds little light on optimal governance structures for the delivery of community-based services (Wanke, Saunders et al, 1995a). The most common organizational structure used within community-based health services is a program structure where the organization's services require much collaboration on the part of service providers (Wanke, Saunders et al, 1995b). Coupled with these complexities and organizational growth are the issues of recruitment and retention of competent, committed staff made more difficult by the multiplicity and diversity of skills desired of applicants (Janz, Wren et al, 1995).

For workers in AIDS-related work, work issues, with the exception of those related to actual patient contact, have received little attention. For example, there is a dearth of information about the organizational structure, management of personnel, delivery of services, and the importance of these factors for the types of demands on staff (McCardle, 1985).

In one large scale study of hospital health professionals' AIDS-related concerns, a wide range of workplace issues were identified including work roles, work assignments and professional authority (Dworkin, Albrecht et al, 1991). Blurring of roles and lack of role clarity have been shown to be important factors associated with psychological distress among volunteers (Raphael, Kelly et al, 1990).

Coyle and Soodin (1992) found that multiple role demands on HIV counsellors was a source of considerable stress (Coyle and Soodin, 1992). Most studies that have examined the impact of HIV/AIDS on workers have not studied the role that staff relationships may play on

work stress. The style of leadership and patterns of interaction may be the source of discontent among nurses rather than the intensity of nursing work (Barbour, 1994). Vachon (Vachon, 1987) found in her study of hospice workers that most of the reported stressors of caregivers were related to difficulties with colleagues and institutional hierarchies.

Despite the importance and impact of volunteers in the care of people with HIV infection and AIDS, they have received scant attention in the literature (Claxton, Catalan et al, 1998). For example, Raphael et al. (Raphael et al, 1990) found that AIDS emotional support volunteers were responsible for the major part of care of PWAs and made a significant contribution to the costs. In San Francisco, it was estimated that the voluntary sector reduced the cost of health care, in 1990 dollars, for a person with AIDS from \$150,000 to \$40,000 annually (Omoto and Snyder, 1990). Similarly in the UK, the value of voluntary services for 1991 was estimated at over £2 million (Partridge, 1992). In 1994 in Ontario, 3,235 volunteers provided 240,995 hours of service at an estimated dollar value of 3.9 million, if volunteer time is equivalent to a person earning a salary of \$33,000 per year (AIDS Bureau, 1995).

Despite the success of emotional support workers, there has been a large drop-out rate, largely attributed to “*burnout*” or psychological distress from chronic work-related stress (Maslach and Jackson, 1982). On the whole, demographic factors, with the exception of age, are not consistently associated with burnout (Guinan, McCallum et al, 1991) but other factors including situational factors to do with organizational structure and interpersonal relationship (Maslach and Jackson, 1981), (Raphael et al, 1990), individual psychological characteristics such as coping style (Bennet and Kelaher, 1994), motivation (Calvert, Flynn et al, 1991), and perceiving the role to be rewarding (Bennet, Ross et al, 1996) have been associated with burnout.

With the increasing need for more complex services in the care and management of HIV/AIDS, support services also have had to change. The changing nature of their work and the increasing numbers of other service providers have put pressure on ASOs to clearly define the scope and nature of their work. In response to this internal appraisal, there has been a move to professionalize support services with a resulting increasing reliance on paid staff members and less demand for volunteers (Cain, 1997). The perceived risk attached to these new demands for services and tighter economic times is that the very nature of ASO work could be changed where ASOs will become like conventional professionally-driven services, where workers, not clients define which services are needed (Cain, 1997).

This complex mix of factors also contains the caveat that the participation of volunteers in health and social services poses several ethical dilemmas including the potential for volunteers to be exploited and alternatively there is the threat that volunteers may pose to paid workers' jobs, role and status (Merrell, 2000).

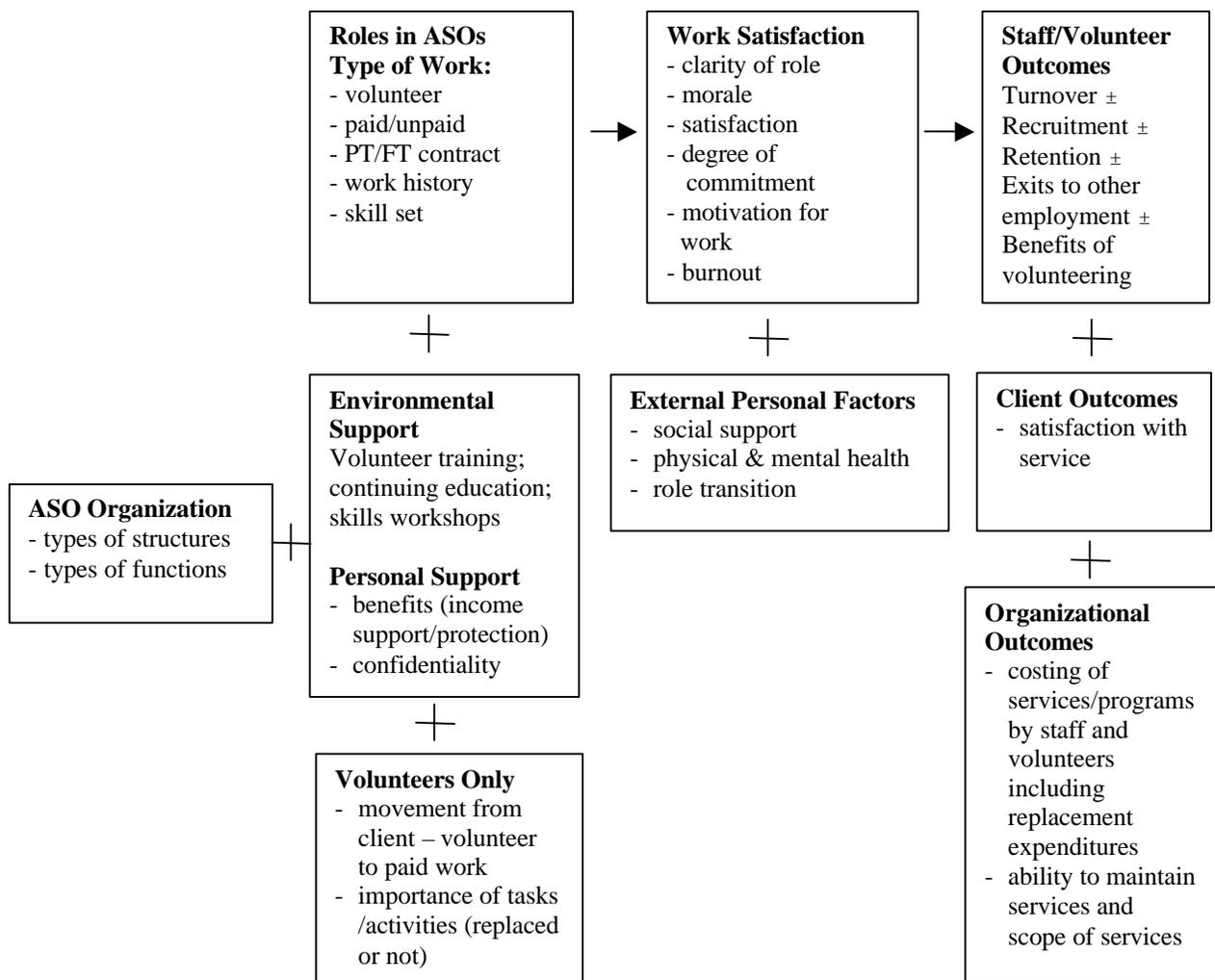
There is a need to develop a better understanding of the work settings, including the structure and function in which AIDS-related work is carried out, and the nature and content of the roles required to do this work. Anecdotal evidence regarding alleged high rates of burnout and turnover amongst staff underlines the importance of establishing which aspects of AIDS-related work are problematic and for which category of worker.

The major study of this theme of research (recruitment and retention) will address some of the gaps in understanding the intraorganizational attributes such as staffing, skills and relationships that characterize the capacity and outcomes of community AIDS Service Organizations. Then such knowledge can better inform guidelines for appropriate recruitment, support systems and training programs (Barbour, 1994).

## Thematic Study Question

The conceptual model of labour force factors, displayed in Figure 1 demonstrates the hypothesized relationships among factors known to influence formal and informal organizational, personnel and client outcomes (Dworkin et al, 1991). The ongoing objective of this study is to test these relationships in order to establish the factors that predict turnover rates in ASOs; the effects of these outcomes on client satisfaction and use of ASO resources; the expense (in-kind and funded) of staff and volunteer services in ASOs.

**Figure 1**  
**Conceptual Framework**



Before this predictive question can be answered, additional information is required that will inform the model. Specifically, the following projects were undertaken to provide the necessary background on which the model is built to describe qualitatively and to quantify as appropriate:

- Project #1 the workplace characteristics, including workplace structure, work roles and client services of the participating community ASOs;
- Project #2 the particular skill sets needed by paid and volunteer staff working in community AIDS organizations;
- Project #3 the estimated financial value of volunteer work to each of the participating community ASOs;
- Project #4 the transitional experiences for people who move, from being a client to volunteer to paid worker;
- Project #5 the experiences and benefits of volunteering in a community AIDS Service Organization.

The main components from this conceptual model that are addressed by each project are identified in Table 1 along with the measures and the methods of data collection.

## **Thematic Study Objective**

### Methods

Six individual ASOs, who responded to the CLEAR Unit's survey for interest in participating in the recruitment/retention/deployment of staff and volunteers project were approached to confirm their participation, elaborate their study questions and their fit into the overall design model (Figure 1 and Table 1).

**Table 1**  
**Overview of Main Areas of Study, Ways of Measuring and Types of Data Collection**

Question	Main Components from Conceptual Framework	Measures	Types of Data Collection
#1	<b>ASO Organization</b> \$ Types of organization structures \$ Board membership, how many/type \$ Policies \$ Function \$ Types of Funding	\$ Structured Questionnaire	Key informant interview - Executive Director - Supervisor/Coordinator - Board Member
#1 and #2	<b>Roles in ASO (staff/volunteer) (focus of role)</b> \$ Nature of paid work in ASOs; e.g., administrative; support/ counselling/service \$ Nature of volunteer work in ASOs e.g., administrative (Board Member); support/counselling	Structured Questionnaire Demographics: \$ work status \$ experience (yrs) \$ where volunteers are coming from e.g., workforce, highschool, other motivation for participation \$ skill set	Key informant - ASO Director - Executive Director - Supervisor/Coordinator - Board Member
#1          #4	<b>Staff and Volunteer Work: Environmental Support</b> \$ Training programs \$ Continuing education \$ Conferences \$ Wages \$ Other Work: Personal Support \$ Benefits \$ Other Volunteers Only \$ The experience of moving from client to volunteer to paid work	\$ Structured Questionnaire \$ numbers taking training form MOH form          \$ Structured Interview	Quantitative \$ Self Report Questionnaire form          Qualitative \$ Individual Interviews
Individual ASO	<b>Work Satisfaction</b> \$ Work environment \$ Satisfaction (fulfillment) \$ Stress \$ Motivation for work \$ Work history \$ Hours of work	Tested Questionnaires \$ Moos Work Environment Scale (Moos and Insel, 1986) \$ Reasons for Volunteerism (Ouellette, Cassel et al, 1995) \$ Workers' role activities \$ Work satisfaction (Mueller and McCloskey, 1990)	Quantitative \$ Self report questionnaires Qualitative \$ Focus Groups
Individual ASO	<b>External to Work (Personal Factors)</b> \$ Mental Health \$ Social Support	\$ Coping style (Moos, Cronkite et al, 1984)	\$ Questionnaire
#1       Individual ASO   #3   #5	<b>Outcomes</b> <u>Staff/Volunteer</u> \$ turnover \$ retention \$ return to work  <u>Client</u> \$ satisfaction with services  <u>Costing</u> \$ all service and programmes by staff & volunteers (including replacement expenditures)  <u>Volunteers Only</u> \$ experiences and benefits of volunteering	ASO data: Key informant \$ structured interview   \$ return to work (Grubb and McClure, 1997)  Service Evaluation Questionnaire (Attkisson and Nguyen, 2000)  Replacement costs: volunteer service costs  \$ Structured Interview	Quantitative (Key informant)   \$ Self Report   \$ Self Report   Qualitative

Interested ASOs included those from urban settings who provide a variety of services to a variety of groups.

Certain critical elements common to all ASOs, such as organizational roles, activities, resources and client services were addressed in each of the participating ASOs. This database will assist in the design of relevant evaluation strategies that will lead to understanding and useful changes.

It was recognized that every ASO serves a different mix of clients, uses different service delivery approaches, defines different outcomes, is at a different place of development and faces different conceptual issues. Therefore, the evaluation process that we developed in this theme of research depended in large part on local conditions and circumstances.

### Design

This is a cross sectional survey with longitudinal follow-up of the cohort and was designed to obtain several different types of data sets from different data sources. The standard organizational and workplace data were collected from the leadership group (Executive Director, Board Member and Supervisor) of each of the organizations through a questionnaire format administered by telephone interview. The questionnaire was mailed to the respondent prior to the telephone interview in order to provide the opportunity for the respondent to obtain certain types of data; e.g., turnover rates.

In addition to these standard data that were collected, each ASO had a specific study question that related overall to the theme of recruitment, retention and turnover but required different types of data from different sources (see Table 1) because of the focus of the question. Both quantitative and qualitative methods were used to answer the relevant study question.

The participation of a number of ASO's allowed for conducting both the specific evaluation project in each of the ASO's but also for the grouping of some of these projects into a larger data set that could together inform policy or planned change for ASO's in Ontario.

### Data Analysis

The conceptual model informs this overall study and guides the project questions. Three levels of project evaluation will be conducted and include:

- a) projects at the individual ASO level;
- b) cluster evaluation, which groups findings from different ASOs;
- c) program and policy making evaluation which uses information gathered from both project level and cluster level to make recommendations about change.

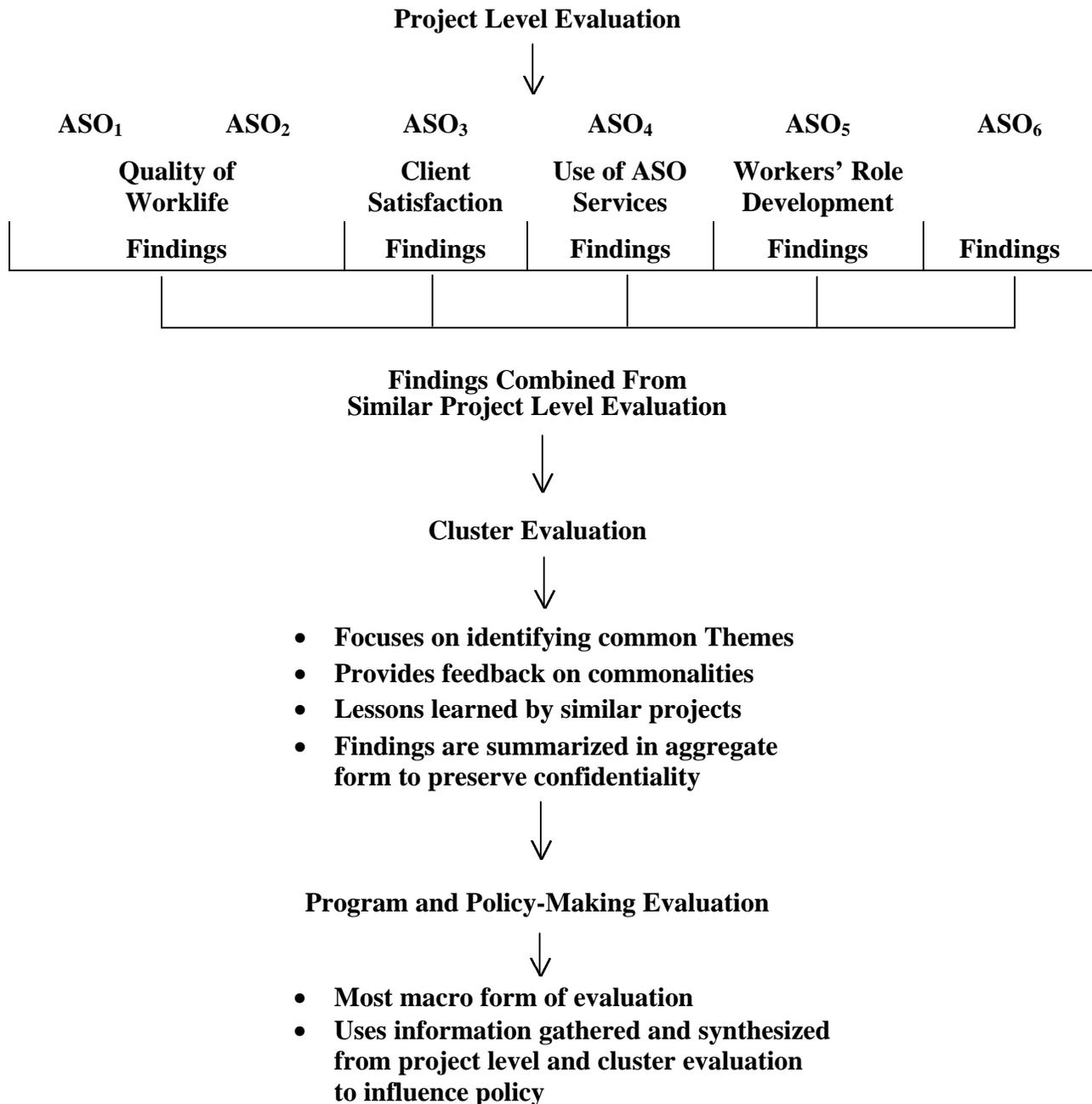
Figure 2 is an illustration of the target of the various levels of evaluation and how this perspective is used in this current study (Kellogg Foundation, 1998). Taken together, the three evaluation levels provide multi-sourced, multi-perspective, multi-level data from which to strengthen and assess individual and groups of projects. This perspective could be of assistance to individual ASOs, the CLEAR Steering Committee, the AIDS Bureau and the Ministry of Health and Long Term Care (MOHLTC) regarding programming and policy work.

### Significance Of The Project

This study attempts to maximize our collective understanding and ability to address the concerns of participating ASOs in Ontario regarding recruitment, retention and deployment of volunteers and staff in AIDS Service Organizations. The study should reveal the factors that

Figure 2

**Levels of Evaluation for Recruitment and Retention Program of Research**



contribute to the stability of the staff and volunteer labour force and the effectiveness and efficiency of the service programmes. The study will identify those factors that are available to use to promote positive change. As one of the largest and most active volunteering groups, it will reveal the economic benefits of marshalling such a force.

Participating ASOs have been closely involved in carrying out this research study. The results should help to improve the ability of ASOs to recruit and retain its staff and volunteers; assist the individual staff/volunteers to maintain and develop meaningful work experience and to improve the ability to maintain services and the scope of services for the changing and evolving “*new face*” of AIDS.

### Research Ethics

This project was conducted in accordance with the following guiding principles:

- a) AIDS Service Organizations must agree to participate and individuals interviewed must be free to give informed consent for the study now and to be approached for later follow up;
- b) The identities of organizations and individuals responding will remain anonymous;
- c) No information collected will be used in any manner by the ASO for performance appraisal or to discriminate against any organization or individual.

This study received ethical approval from McMaster University Research Ethics Board. All participants provided informed consent prior to participating in the interviews and/or completing the questionnaires.

**PART #4**

**WHAT ARE THE TRANSITIONAL EXPERIENCES  
FOR PEOPLE WHO MOVE FROM BEING A CLIENT  
TO VOLUNTEER TO PAID WORKER?**

**Joan Crook  
Robin Weir  
Dennis Willms**



## **PART #4**

### **WHAT ARE THE TRANSITIONAL EXPERIENCES FOR PEOPLE WHO MOVE FROM BEING A CLIENT TO VOLUNTEER TO PAID WORKER?**

**Joan Crook, Robin Weir, Dennis Willms**

#### **Executive Summary**

This paper explores how individuals come to understand and give meaning to difficult transitions in their life triggered by knowledge of positive HIV status in themselves or in close friends. In particular, this qualitative study seeks to understand the transformation of meanings which come to be constructed by individuals in response to four major transitional events that began with hearing the news of positive HIV status. Subsequent events included leaving paid work, volunteering in an AIDS Service Organization and consideration of returning to paid work.

All participants were recruited through 6 ASOs in Ontario and had a history of volunteering. There were 18 interviewees that included 16 males and 2 females. The HIV status of 15 participants was positive and for 3, negative.

Each participant identified “hearing the diagnosis of positive HIV status” in themselves or in their family member/friend as a pivotal transitional event that “cut the participant to the quick” (Willms, 2001). This event was the first stage in the process of transformation as the participants tried to reconstruct their lives in the face of adversity and loss occasioned by the diagnosis.

Each of the transitional events that were described called the participants assumptions about life into question. However, these events also provided participants with an opportunity

for thinking and acting differently as they tried to reconstruct meaning after their normal every day mode of existing was shattered. A model was developed from the participants' stories.

There were three transformative phases that could be identified within each of the transitional events. The first transformative phase is described as a major disruption to the way we live in the world. At hearing the diagnosis of positive HIV status the participants became aware of the realization that existence could be threatened by non-existence and that at some future moment they would not be. The whole being, therefore, must cope physiologically, socially and interdependently.

The second transformative phase is that characterized by the participants as "belonging and affiliation". In this phase, the participants took control of their own destiny by looking at themselves as a whole and in relationship to others. As they took control and tried to contain their suffering (Hall, 2001), they reached out to their world and others around them. This phase was a catalyst toward trying to live a life that reflected a more nurturing, honest and authentic approach to relationships.

The third transformative phase reflects what we have identified as "becoming", a process of transformation to find meaning, a human empowerment. This phase represents a reappraisal of the way life is lived or the way in which emotional strength is found.

The model implies movement through these transformative phases which were described as being, belonging and becoming, toward an illusive something, not fully defined but best described as self-actualization or self-growth (Maslow, 1954),(Alderfer, 1969) whose choice is to give meaning, value and purpose to his/her life.

## **Purpose**

This paper explores how individuals come to understand and give meaning to difficult transitions in their life triggered by knowledge of positive HIV status in themselves or in close friends. The opportunities for new self interpretation that exist in situations which dislodge that which had previously been relied upon to give life meaning and direction are explored. In particular, this study seeks to understand the transformation of meanings, which come to be constructed by individuals in response to four major transitional events that began with hearing the news of positive HIV status. Subsequent events include leaving paid work, volunteering in an AIDS Service Organization (ASO) and consideration of returning to paid work.

Many volunteers in ASOs, particularly in the past, began as clients infected/affected by positive HIV status. It has been informally observed by those working in ASOs that the experience of volunteering transforms the volunteer into a person with more self esteem, confidence, and connectedness to a social network. This in turn, gives the volunteer a new purpose in life. Accordingly, volunteers become an important source of wealth generation either in their paid or unpaid work at a specific ASO or elsewhere.

By analyzing the shared experiences that people engage in, in order to restore meaning to their experience after hearing the news of positive HIV status, new ways of thinking about and responding to each critical transitional event may emerge. These new possibilities may have implications for those working in ASOs given their commitment to care for those affected and infected by HIV during times when meaning breaks down. The presence of concern, nurturing and caring has far reaching implications at these transitional events.

The objectives of the qualitative study of the transitions of clients to paid or unpaid (volunteer) work were three fold: to document the story of the transformation from hearing the

news of positive HIV status in themselves, friends or family members, to becoming a volunteer, or from being a volunteer to becoming a paid employee; and to identify the mechanisms by which this happened from the point of view of the volunteer.

The third objective is in knowing to what volunteers attribute this change, and whether any of this change is due to the experience of recruitment, nurturing, acknowledgment and changing expectations provided by the ASO as ways of retaining and “growing” the competence of these individuals.

In this qualitative study conducted within 6 AIDS Service Organizations, we were concerned with understanding the experience of transformation that individuals go through as they move from being a client to becoming a volunteer, and/or from being a volunteer to becoming a paid employee.

## **Method**

As we are interested in understanding the lived experiences of ASO volunteers, we employed a phenomenological and grounded theory of method inquiry. Research questions were developed which explored the meaning of a particular experience for individuals, and reflections were collected from those individuals who have experienced the phenomenon under investigation (Appendix A). Building upon this understanding, the grounded theory approach was used to explore the social processes that occurred at each transition with the goal of developing theory. This study used a qualitative approach in the form of one-on-one, audio taped, in-depth interviews with volunteers and paid staff in 6 ASOs in Ontario.

Theoretical sampling was used to designate potential study participants. This allowed the selection of subjects who could illuminate the phenomenon being studied. For this study, 18

volunteers were chosen to take part in the in-depth interviews, from a range, which included volunteers who used to be clients (infected by HIV/AIDS), or those affected by HIV/AIDS and paid workers who used to be volunteers.

### **Ethical Issues In The Qualitative Study**

Written informed consent was obtained prior to each interview (Appendix B). Only the participants, and the research team had access to interview tapes and transcripts. Tapes and transcriptions of interviews were kept in a locked location, accessible only to the research team. All responses were confidential. Any quotations used in any report for publication are attributed anonymously.

### **Analysis In The Qualitative Study**

To maintain consistency in data collection, all data was gathered by the same interviewer. The audiotapes from the in-depth interviews were transcribed verbatim, and all participants had the opportunity to review his/her transcript to check the accuracy of its content.

Data obtained from the interviews underwent interpretive thematic analysis, involving a review of the interview texts as a whole for an overall understanding, followed by repeated reading of the texts to look for patterns of regularities, recurring ideas and experiences that linked or distinguished participants' perspectives. Analysis was enhanced by the use of the NVivo program, designed specifically for use in qualitative data analysis. Emergent themes and recurring ideas from the data regarding the transformational experience of volunteers as they reflected on the transitions from the response to being infected or affected by HIV/AIDS

diagnosis, to leaving paid work, becoming a volunteer and/or returning to paid work were generated (Appendix C).

When the initial phase of analysis was complete, validity was enhanced by bringing participants back together for a one-day workshop to review findings and to check on the accuracy of interpretation. Collectively the original model was reinterpreted to indicate the dynamics of the relationship between transitional events and transformational phases. This input created new labels for some of the themes, and new models linking themes; however, major concepts and themes remained the same.

## **Participants**

Participants were selected based on their ability to illuminate the phenomenon being studied and were chosen if they had been infected or affected by HIV/AIDS and were presently volunteering at an ASO or had done so in the past and were now employed.

Participants were recruited through 6 ASOs in Ontario. There were 18 interviewees that included 16 males and 2 females. The HIV status of 15 participants was positive and for 3 negative. A mean of 9 years from diagnosis (range 2-18 years) was noted for those with positive HIV status. While all participants had a history of volunteering, twelve participants were currently paid employees (8 in ASOs; 4 outside), and 6 participants were on disability pensions.

## **Results**

Participants were asked to think back to the time before they became volunteers (Appendix A). Each participant identified “hearing the diagnosis of positive HIV status” in themselves or in their family member/friend as a pivotal transitional event, that “cut the

participant to the quick” (Willms, 2001). This event became the common denominator that tied each story together. This event was the first stage in the process of transformation as the participants tried to reconstruct their lives in the face of adversity and loss occasioned by the diagnosis. The transitional events that followed were identified as leaving paid work occasioned by positive HIV status; becoming a volunteer and/or returning to paid work.

Each of the transitional events that were described called the participants assumptions about life into question. However, these events also provided participants with an opportunity for thinking and acting differently as they tried to reconstruct meaning after their normal every day mode of existing was shattered. A model was developed from the participants stories (Table 1).

There were three transformative phases that could be identified within each of these transitional events. The first transformative phase is described as a major disruption to the way we live in the world. In the phase of experiencing suffering and loss (Hall, 2001) there is a state of “being” in that small space of the body. At hearing the diagnosis of positive HIV status, the participants became aware of the realization that existence could be threatened by non-existence and that at some future moment they would not be. The whole being, therefore, must cope physiologically, psychologically, socially and interdependently.

The second transformative phase is that characterized by the participants as “belonging and affiliation”. In this phase, the participants appeared to take control of their own destiny by looking at themselves as a whole and in relationship to others. As they took control and tried to contain their suffering (Hall, 2001), they reached out to their world and others around them. This phase was a catalyst toward trying to live a life that reflected a more honest and authentic approach to relationships.

**Table 1**

**Constructing Meaning from Transitions  
Ongoing Transformative Process to Reduce the Risk of Further Suffering and Loss**

<b>T r a n s i t i o n a l  E v e n t s</b>	<b>Transitional Events</b>	<b>Being (Experiencing Suffering)</b>	<b>Belonging (Containing Suffering)</b>	<b>Becoming (Transforming Suffering)</b>
	<b>Hearing the Diagnosis</b>	<b>Experiencing Loss</b> \$ Life Crisis \$ Chaos	<b>Confronting Loss/ Establishing Control</b> \$ I am more than my disease \$ I need help	<b>Recognizing Purpose in Life</b> \$ Moving on \$ Leaving a legacy \$ Redefining self
	<b>Leaving Work</b>	\$		
		Losses in the workplace \$ Life without work \$ Loss of relationships	\$ Benefits of leaving \$ Finding self	
	<b>Volunteering</b>		\$ Personal growth \$ Paralleling \$ Belonging/affiliation	\$ Personal values enhanced \$ Part of upbringing \$ Self competency
<b>Returning to Paid Work</b>	\$ Worries -about benefits -about how treated -about illness uncertainty -about workforce absence	\$ Education in workplace \$ Assistance in RTW \$ Taking personal control	\$ Starting to dream \$ Finding new meaning in life	

“Being occurs basically at the level of the grasping of oneself” (May, 1983)

The third transformative phase reflects what we have identified as “becoming”, a process of transformation (what Hall (Hall, 2001) calls a transformation of suffering). We broadened Hall’s concept to consider the concept of finding meaning, a human empowerment. This phase represents a reappraisal of the way life is lived or the way in which emotional strength is found.

In Figure 1, we represent pictorially transformational phases as a dynamic process, constantly changing; the transitional event is the catalyst, which challenges the participants assumptions about everyday life into question. Participants shift back and forth between transitional events and transformational phases. As one participant said so pointedly:

*“I’ve been receiving diagnoses for the last 18 years - everything from cancer, thrush, hepatitis and so on. From August 10<sup>th</sup> to 25<sup>th</sup> of this year I stopped working (I was) in so much pain that I thought I was going to die and here I am today talking to you. I find that incredible. In the last 4 years this condition has happened over and over again.”*

Each of these transitional events and transformational phases will be developed in more detail in the following pages. (See also Appendix D)

### **Transitional Event: Hearing The Diagnosis**

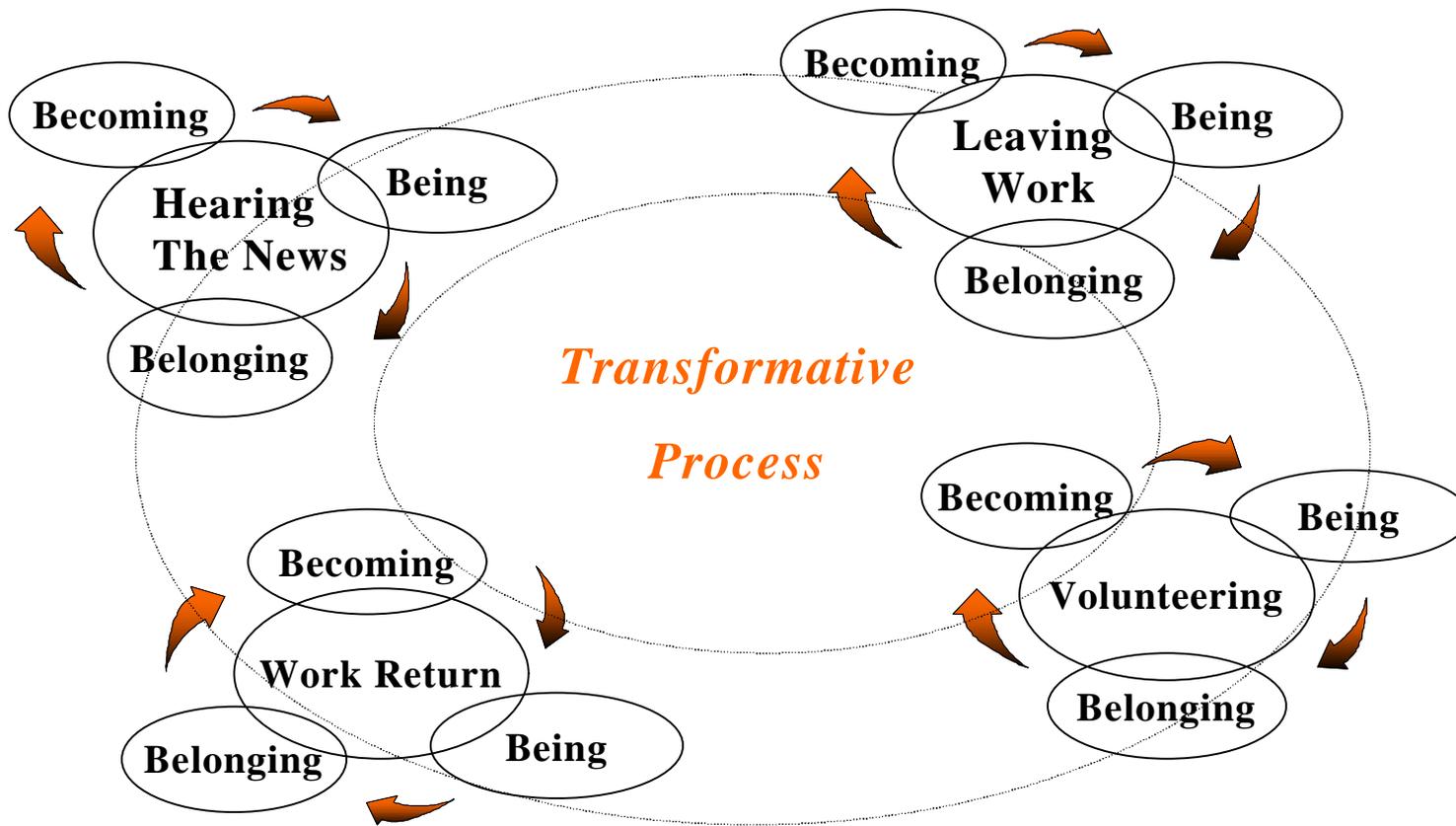
#### Transformative Phase: Being; (Experiencing Suffering)

Hearing the diagnosis of a positive HIV state in self or other shattered the normal, everyday mode of existing for the participant. Participants spoke of the crisis it caused and the suffering that accompanied the diagnosis:

*“I ended up getting into a very different situation which almost killed me”*

An acute illness reaction accompanied the diagnosis for some:

***“Being, Belonging, Becoming”...***



**Figure 1**

*“I went in and stayed 2 weeks in hospital and was discharged - there was not confirmation of the test. About a week later I ended up going back for a second time and was released a week later. Another 2 weeks went by and I got sick again. I was sent to another hospital”*

Another participant reflected to that time of diagnosis:

*“I was dying because I got to the point where I just lost it and I was about to give up.”*

Participants who came to know of their diagnosis through testing (e.g. pregnancy) but not being aware of any symptoms spoke of disbelief; a response that influenced repeated testing:

*“No test me again! This cannot be! You Know! NO! NO! I mean this cannot be happening!”*

The other reaction participants noted was the untimeliness of the diagnosis in reference to a particular time in the person’s life:

*“I had already stopped working and was getting ready to move to the U.S. but I got sick and had to cancel the trip.”*

While a diagnosis of HIV/AIDS is never timely, the diagnosis became connected to everything else that was happening in the person’s life or the new directions that were chosen and then lost.

Participants faced multiple losses and challenges. There were overwhelming fears of “loneliness”, “rejection” and “dying”. The stigma and shame the participants felt was hurtful and this resulted in lowered self-esteem:

*“AIDS was taboo, it wasn’t talked about. I couldn’t go for a medical to my own doctor.”  
“It happened here in Canada of people who tell their friends (they have AIDS) and they have to leave their apartment because of the graffiti. They know it is the ‘dead beast’”*

Another participant commented:

*“And I was embarrassed and I put my head down because I felt maybe everybody looked at you and they’d say; ‘Oh, he’s positive.’”*

Losses were perceived not only immediately, but also continuously as the disease progressed:

*“I resent having to let go. I cut out so much of my life. I resent having to make the choice to cut out even more, as the years go by. Promises of me getting better and better have yet to come true.”*

This place of “being”, experiencing suffering and facing multiple losses and challenges to the self was characterized by a focus on the body, the symptoms, the side effects of medications, and the virus, and could best be described as “I am my disease”. One participant noted:

*“I have been really inside my body for about 4 - 5 years.”*

And another:

*“I have been sick since day one. Medication: I had all the side effects imaginable and more.”*

Some medications are reported as having “such horrendous side effects”:

*“I get up in the AM and have 2 hours of diarrhea and nausea.”*

The physical effects of the virus, the side effects of the medications and the demands of the drug regimens pushed some participants into withdrawal:

*“...all I was doing was just sitting at home wasting my time, not doing anything.”*

And it often took a long time before participants came to grips with their new reality:

*“I am diagnosed with HIV and I didn’t know how to handle it and it took me a year to face the fact, to absorb it.”*

Discussion occurred during the workshop about the suffering caused by communicating each of the diagnoses as the disease progressed to his/her family.

*“...each time I’m in the hospital, I make that phone call home to let my family know; and it’s extremely difficult to do because each time you do, it has an impact on them. I remember my father called me one day while I was still hooked up (to morphine) and it was so difficult to communicate with him...and also the concern in his voice, hearing his*

*son and he knows what I'm going through, he knows I've suffered a lot over the years and he knows that I'm going to fight each and every time it happens."*

### Transformative Phase: Belonging (Containing Suffering)

Participants appeared to gain, and for some, to seize control of their own destiny as they confronted the impact their disease had on them. One participant described his decision to move beyond his disease very clearly:

*"OK, enough of this bullshit. Now it's time to take my life into my own hands."*

This attempt to move beyond the suffering influenced some to stop their medications:

*"I got off the medication because of toxicity levels and my body rejecting the medication...so I was able to sort of get out of my body and my mind kicked in."*

Others made healthy lifestyle decisions as a way of containing their suffering:

*"Definitely in terms of my health, in terms of my life, in terms of my relationships, in terms of what was important and what wasn't, learning to say no."*

For some, the unpredictability of their illness caused them to postpone taking a decisive step to move beyond their body, and it's pain:

*"I can't wait around for another 10 years. I mean I just sat around for 10 years, did nothing, was broke, while all my friends were living and doing things. So I said I can't do this again."*

Most notable as participants came to realize at a profound level that they were more than their disease, was their recognition that they needed help. This recognition propelled them to reach out to each other and find support. One participant reflected what others felt:

*"I do need help and I need all the help I can get so let's just dispense with this little bit of wall that I've got up there and knock it over and go with the flow."*

Although asking for help was not always easy for several participants:

*"I was embarrassed to come here (ASO) first, very embarrassed. It took me nearly 6 months to feel comfortable."*

### Transformative Phase: Becoming (Transforming Suffering)

The third phase of the transformation was labeled as becoming. Becoming represents a reappraisal of the way life is lived. It is the recognition of one's potential to grow and enhance the meaning of life for one's self. Becoming reflects the capacity to see oneself as a "being in progress". As one participant said, it (the diagnosis)

*"...was devastating at the time but then so many good things have come from it and for me, I think it put me on a much better path than where I was."*

Priorities are redefined:

*"It was a good wake up call. It's been one of the best things that ever happened to me just in terms of prioritizing what's important in my life."*

Confronting his/her depression and the possibility of death led one participant to recognize the importance of living for his/her child and leaving a legacy:

*"I found out my child was negative, I thought, Oh God, I have to live now."*

### **Transitional Event: Leaving Work**

#### Transformative Phase: Being (Experiencing Suffering)

The next transitional event that emerged from the interviews was leaving work and career. Participants talked about the struggle to maintain in the workforce, experiencing suffering while they tried to do so.

Some participants tried to keep their diagnosis a secret:

*"Where I worked nobody knew about it."*

And another stated:

*"I mean, work is a big part of your life...so having to hide a lot, a lot of the realities of my life, particularly my status and all the concerns that that would bring..."*

However, as the struggle continued, it became more and more difficult to keep the secret:

*“To see a person deteriorate that rapidly...rumors are going to start...and the girl who approached me...made it clear that they’re not saying bad things...they’re just saying we think he has AIDS...but it made me uncomfortable knowing that people were talking about me like that as opposed to coming to me and saying...what’s going on.”*

Another described what happened when the secret got out:

*“...they had gone through the place and told everyone that I had AIDS, and it changed the whole demographics of the workplace...I mean everybody was terrified of using the same washrooms - all those things.”*

Often leaving work was a choiceless-choice (Willms, 2001) due to being “found out”, deteriorating health, uncertainty regarding the future, loss of physical strength and side effects of drugs.

*“I was downsized out...I was off for about three months and I guess that was when the company found out my status...when they found out, my employer decided that they would put me back to starting position...demote me...take away my status, take away my benefits, my seniority...all those things...you know...I should consider myself lucky because they could fire me...”*

Others left work on physician’s advice:

*“So I left work right away...I did what he (the doctor) said...for me I had always been a type of person who worked lots...I loved to work...I enjoy working.”*

Deteriorating health and the ill effects of the drugs put some participants in a “Catch 22” position:

*“The drugs themselves have caused some problems with weight...so you know every now and then if I’m not feeling well and a little down and someone does a double take. I think oh it’s my face...they believe the drugs are causing this so I’m in sort of a catch 22 - damned if I do and damned if I don’t...if I take these drugs I’m going to suffer...some drugs cause massive hallucinations, unbelievable paranoia and convulsions.”*

*“I was asking too much of myself...I was one of the rare ones who was sick from day one...I have had all the side effects imaginable and more from the medications.”*

Losing the opportunity to work was a major component of participants suffering and loss:

*“...and I was throwing up 20 to 30 times a day because of the medications I was taking...but I didn’t want to leave work...by the time I developed cancer I was tired and I had decided enough is enough.”*

*“Well basically I left work...after being diagnosed with ...cancer...which required me to have a tube inserted into my chest and put IV into on a daily basis...very difficult.”*

The physical demands of the job brought others to the realization of the difficulty of staying on the job. As one participant noted:

*“But because it’s (the job) physical and it was not really good for me, for my health...that got me depressed, that I felt I was not going to be able to do the physical work...”*

Another participant suggested that if he were able to modify his job, he could continue to work.

*“Being what I used to do often before, I can’t stand on my legs all the time, but if they let me sit down more often, I would do it.”*

Any anticipation of the future was filled with uncertainty. This made planning difficult:

*“Like am I willing to invest three years of my life to go back to school if I may only have three years left?...even though people are not dying fast, there is always that motivation.”*

Work is important: it gives men and women a sense of identity, purpose and meaningful existence. Security, self-esteem and the ability to make key life decisions have been associated with gainful employment. It follows that the loss of occupation threatens the emotional, psychological, financial and social well-being of the individual. This conflict was identified by the participant who said:

*“So when I went on long term, it was a very big struggle for me as to who I am now...what do I see myself doing, and of course the first thing people ask you when you’re out is this; what do you do for a living - and I didn’t have anything to say.”*

Losing the opportunity to work was a sad and unfortunate consequence often of other persons’ decisions. Subtle and not so subtle, pressures suggest that the person with HIV/AIDS was not welcome in the workforce anymore.

After the decision was finally made, that choiceless-choice, most suffered the change in self-esteem of not being employed and the loss of the financial status previously held:

*“Yes. Initially, yes. It was, it was, horrible, I’m just finishing up a mortgage. That was another reason for getting back to work. That was my, like my home. I need to have a home base so that was important for me. But, I was having to eat Kraft Dinner. I had to go to that seconds shelf and stuff like that. Didn’t like that. Shopping at Bi-way instead just for underwear.”*

*“But I was paying, yea, like \$200 rent so it left me then with, I think, about \$400, and I was paying about \$150 a month on vitamins and natural supplements and those kind of things. I had my little \$15 Y membership. And other than that it was poverty basically.”*

Not having money to do the simple social things that bring pleasure to life forced participants to find new relationships and new activities to do:

*“I’d been off work 3, 3 1/2 years, so finances were tight. For me to go for a coffee was,...I had to watch my money quite a bit. So originally when I started coming (to the ASO) it was to do something, you know, with my time, to come to the coffee shop to meet people, just to have something to do.”*

As one participant remarked:

*“But, yea, it took me about 6 months to sort of come around to finding something else. Finding something else to do. It was, it was a very tough 6 months to get through. And I think, well I think it’s probably what our parents go through when they retire. You know it’s like I’ve done this all my life and now what. I, I don’t work or I can’t work anymore now, what do I do? Who am I now?”*

Leaving work forced participants into dealing with the government bureaucracy for employment insurance, social assistance, disability programs, drug benefit programs and so on. They had to learn the rules of the benefits game and suffer the indignity of needing assistance:

*“You don’t have any say in the matter and you know they were so clear about you can’t make any money. If you get caught they’ll cut you off, you’ll never get medications, nothing available to you. And I mean it’s, there’s that fear there that is so intense.”*

As one participant noted:

*“But here it’s very, you know, follow the rules. And I was a good Catholic boy so you follow the rules.”*

Another participant realized:

*“I think most people with this illness who are on social assistance are trapped. I have friends that have worked and never stopped working. And um, they...I don’t know if they are envious or um, they sort of call us ‘free loaders’ sometimes when we are on social assistance. But those friends are also people that worked at \$60,000 a year jobs with excellent benefits that when they do stop working, they are still going to make more money than I was making at my job.”*

#### Transformative Phase: Belonging (Containing Suffering)

As participants began to face the loss of work, and establish some control, they began to realize some of the health benefits of leaving work and began to consider new options:

*“...and this is before any of the medications I went on...my immune system strengthened quite a bit after I stopped working...the doctor said it was because I was less stressed.”*  
*“...maybe it was also the encouragement of the counselor...and it was like I saw his role and what he was doing and felt that this is something I could do and do very well.”*

#### Transformative Phase: Becoming (Transforming Suffering)

When participants reached out to others and considered volunteering, it represented a kind of shift towards a “different moral awareness personally and socially”, not just about relationships - individuals affecting social change (Willms, 2001). Willms, (Willms, 2001) summed the discussion with the participants:

*“It’s not just about me any more....but there is a sense in this domain, that we’re talking about a kind of ethical imperative...that is quite profound as you enter, if you will, a space of being, belonging, and becoming, you know, differently.”*

#### **Transitional Event: Volunteering**

#### Transformative Phase: Being (Experiencing Suffering)

One of the biggest losses for participants when they left work was the loss of relationships. Recognizing this loss was reflected in the need to belong that participants

expressed: needing “a sense of connection” and needing “to be needed and loved and respected”. One participant recognized that “loneliness is a killer”. With this recognition, participants began to reach out and began “to meet other gay people and be part of a community”. Part of the motivation was...

*“To relieve boredom - to get more in my life because I have always worked.”*

These factors became the motivating forces that led participants to consider volunteering at an ASO.

#### Transformative Phase: Belonging (Containing Suffering)

Participants confronted their loss of work and the impact HIV/AIDS had on their lives through volunteering in an ASO. Participants talked about developing “a sense of contributing again” and wanting “to give something back to the community” or “wanting to be able to assist a friend who was living with HIV”. One participant, but echoed by others, stated clearly:

*“My whole idea behind it (volunteering) was because so much was done for me...through being a client...this organization has done a lot for me and I’ve got to give something back to them.”*

Several participants identified their desire “to share their personal experiences” through contact with others:

*“It was people contact...that interpersonal contact...and seeing these people who come through the door who were where I was a year before...so that was exciting to be able to share some of that with them when you could just see the panic and fear and you knew they were in such a scary place.”*

The motivation to share with others could only come after the volunteer recognized the he/she had something important to share:

*“I learned stuff and I could share some of that stuff.”*

Another volunteer noted:

*“It’s connecting with a sufferer...contributing to others...turns shame around ‘cause you have no time to think about it.”*

*“Coming to terms with my own experience and it’s meaning, sharing my own experience and supporting others in theirs”* was important for one volunteer.

In a similar vein, another noted:

*“Offering my own experience to help others: a gift of my own experience and success in living.”*

In addition, another noted:

*“And I would talk about my experience and listen to them (clients)...kind of giving them hope.”*

There were several motivations that prompted those infected/affected by HIV/AIDS to volunteer as noted above in the words of the participants. There were some realizations that the volunteers identified that promoted their continuing involvement in volunteering at an ASO.

Firstly, some noted that volunteering:

*“was a lifeline...(it) provided relief, a sense of peace, serenity, a life preserver when I stopped working.”*

*“helped center myself...I don’t dwell on being sick...don’t wallow in self pity.”*

Another noted:

*“It’s giving you something every day to make you feel like you want to be there.”*

One volunteer identified three important components of his/her continuing involvement:

*“...being a volunteer gave me the opening to get information and stay abreast of what was happening...and I was freshly out of the closet and so excited and wanting to engage the world and this felt like a good place to do that...and it seemed like it would be a great place to meet other gay people and build a community and be part of a community that already existed.”*

Omoto and Snyder (Omoto and Snyder, 1993) argue that to the extent that volunteers are satisfied with their work, they would likely continue their volunteer activities. Volunteers who enjoy their work and see the benefit for themselves and believe in its importance for others are likely to maintain their involvement in the ASO. One participant thought that every experience was important:

*“I think for me every experience is contributing to my growth.”*

Some noted that volunteering:

*“helped my confidence...made me realize I can do a lot more and be a better person for myself and for others.”*

For another the benefit of volunteering was

*“control over life...peace of mind, learning and doing something I liked.”*

The participants noted improvement in their mental and physical health that they associated with volunteering:

*“My physical health has improved, increased physical endurance, and increased sense of well-being.”*

One volunteer commented that his/her partner said:

*“‘You don’t talk about dying anymore.’ and I said ‘it’s not that I don’t think about it, it’s just that I don’t talk about it anymore because I’m not thinking about dying anymore, I’m thinking about moving on.’”*

Another volunteer said:

*“I’m looking forward to the rest of my life because of the people that I’m surrounded by and they give me a lot of encouragement.”*

One volunteer, in working with clients noted:

*“Getting busy gets them over the depression, with less meds, which is really important to me because I see a lot of people that are so heavily medicated that they can’t function.”*

One of the volunteers unexpectedly found him/herself able to do things beyond the realm of what he/she thought possible:

*“You know, here I am dying...then I come down here and I am moving 80lb. banana boxes full of tin cans and sorting them...and I think, ‘I can’t be that sick!’”*

There were other rewards with volunteering that participants identified. One volunteer noted:

*“Volunteering was a place to grow...works both ways...helps you grow so that you feel life is giving me back something. Volunteering allowed me to examine meaning in my life, managing my condition.”*

Belonging and affiliation with others made volunteers feel valued and attached to something greater than themselves, that is, others:

*“...helping out any way I can...they appreciate my help...I made a big change in their lives...making a difference.”*

The ASO where they volunteered was identified as “a welcome place”, where “we will help you, too...we will empower you”. Volunteering at an ASO

*“...opened doors for me with people who needed to know that I understood some piece of their oppression.”*

It was important for some to realize:

*“You’re in the same environment as people who are the same as you.”*

Other volunteers commented on the importance of belonging:

*“They like me a lot...they like the work I do...”*

or another:

*“They like me, they like me...I am reminded constantly that I am a very good worker, very good with other people.”*

For others volunteering offered a place in which one could

*“just hang out and be with people...we have a laugh...knowing there is always somebody to talk to.”*

Volunteers, and our participants were no exception, constantly said that they got more than they gave through their volunteer work. Luks, (Luks, 1988), noted that volunteers often talk about coming away from the experience physically, emotionally and socially recharged. He called this the “helpers high” and identified that one of the most important characteristics of the volunteer work involved working with other people.

It was clear from this transformative phase, “belonging”, that participants, through volunteering, began to take control of their own destiny by looking at some of the benefits they received from giving of themselves to others and reaching out to others. They recognized that they were needed and that their contributions were relevant and what they had to offer made a difference to others infected/ affected by HIV/AIDS, to the ASO and to themselves.

#### Transformative Phase: Becoming (Transforming Suffering)

Participants in this study were all current or former volunteers. Many found critical new meaning for themselves over the course of their volunteer work. Volunteering at an ASO helped the participants to recognize their potential to grow and enhance the meaning in their lives. One participant noted:

*“A tree in a cave cannot bear fruit.”*

as he/she realized the importance of reaching out to others. Another recognized that self-awareness was nurtured through volunteering:

*“...to kind of find myself and, yeah, know who I am.”*

Personal values were enhanced:

*“Volunteer work is good in itself and there is not always an expectation to move on...no agenda.”*

Another volunteer noted his/her growth since he/she heard his/her diagnosis:

*“I found out I was HIV positive myself...and I promised myself I would volunteer at an AIDS organization...and now that I was not working I had the time...and I am more responsible these days, so I went for it...that was a promise I made to myself when I was drinking.”*

New values were identified that included “letting go of judgements and becoming more compassionate”.

### **Transitional Event: Returning To Paid Work**

#### Transformative Phase: Being (Experiencing Suffering)

The thoughts of participants when they considered a potential return to paid employment were complicated, uncertain and conflictual. On the one hand, paid work offered legitimacy and was a statement of social responsibility. One participant commented:

*“If you didn’t know I was HIV, like I fit into society again. I’m working, I have, well I have two jobs, plus the volunteer thing, and I don’t have to lie to people. You know if you meet somebody or whatever, I am working. It’s important. People don’t like you if you’re not working - as much.”*

For another, it was:

*“Independence; it gets you back in the fast lane.”*

but being of “two minds” was always present in the participants’ narratives:

*“I guess I’m struggling a bit with going back to work. I mean my initial reaction was - work, why the hell would I want to do something like that (laughs) but on the other hand it’s kind of exciting too because...wow...becoming more independent feels good.”*

There were many potential losses and fears that participants faced and risks that had to be acknowledged when they considered a return to paid work. The loss of benefits under various

government disability and insurance programs, potential discrimination in the workplace because of positive HIV status, uncertainty of the illness trajectory, uncertainty of the side effects, and toxicities of the drugs were ever present.

One participant summed his/her fears:

*“The whole process of going back to work is very frightening...we might lose what we have.”*

The potential loss of benefits weighed heavily on participants:

*“You know, somebody loses their job, they lose their benefits, they go on to Employment Insurance...they have no drug coverage there...then what am I going to do?”*

and:

*“...well if you don't have a drug plan...there's no possibility for you to afford treatment.”*

The uncertainty of the illness trajectory and toxicities of the drugs is the one certainty all participants faced:

*“...one thing we know...I will get sick again... the medication will fail...I will get sick from the toxicities or it just won't work anymore...or I will become resistant...so I go back to being protected again...what happens if I lose my job again...I have got to go back and sell myself on the market and the older I get the more difficult it gets...it plays on my psyche...my self worth.”*

The impact of the uncertainty of the effectiveness of the drugs and the illness trajectory was identified by one participant:

*“...well I've been in that situation where I've been feeling better...and maybe I can go back to work and boom - something happens...and that's how quickly things can happen if the drugs stop working...if your t-cell count starts dropping your health can start deteriorating quickly...if I go back to work and get sick, what's going to happen to me...I'm going to lose that job.”*

Returning to the work force can be more difficult if the visible signs of illness are present:

*“...if they’re sick...if there’s any kind of like caved in cheeks, lack of weight... any outward appearance that you’re sick...trying to go into a new environment and hide it from people is more difficult...”*

The workplace itself poses problems for re-entry. That some workplaces will not hire those who are HIV positive was reported by some participants. Other participants commented:

*“There’s some jobs out there that say they don’t care you’re HIV positive.. Then they’ll turn around and fire you because you’re taking off so much time because you’re sick...that’s discrimination.”*

One participant had a pleasant surprise when he/she applied for a job:

*“They’re going to have a reason not to give me insurance...and he (the employer) says we have to send in an application...tell them the truth and let them decide...don’t worry about anyone knowing...it’s confidential...and to my surprise they covered me.”*

How they will account for their long absences from the workforce, caused several participants concern:

*“What am I going to say?...well I have been off work for 5,6 years because I have AIDS?”*

but one participant used the experience he obtained as a volunteer and reported it as job experience:

*“Like I said on my resume a couple of years ago and I didn’t put down volunteer...I put down reception as job experience...I didn’t put it as a volunteer job and then it doesn’t look like I stopped working for a long time either...”*

Some participants recognized that being out of the workforce for a long time made their skills redundant and their confidence depleted:

*“There’s also people that have been off work for 10-12 years and they don’t have the confidence...you have to know about computers and you have to know about this and that...”*

Another participant felt that fear of stress in the work environment and lack of experience contributed to difficulties entering the workforce:

*“It’s obviously a very personal thing...some people can’t get into the work environment because it’s either too stressful, they’re not experienced or they have a self image problem...”*

Other participants worried about discrimination in the workplace:

*“...and they’re whispering behind your back...that’s the toughie to deal with getting back in the workforce because they do have employees that are very homophobic, that don’t like working with gay people, that are very judgmental...”*

In a similar vein, another participant commented:

*“...if I went back to work I would be fully disclosing the fact that I have AIDS... If I go back to work am I going to worry about whether you’re afraid to come near me...”*

Worries about being discriminated against were a prevalent concern:

*“You know being ill is difficult enough in itself - but as a person with AIDS if I go back to work am I going to have to worry about whether you’re afraid to come near me.”*

*“...and that is a concern for a lot of PHAs... is having to be open at work about being PHA and the discrimination around that.”*

The lack of clarity regarding benefits is a confusing path to travel:

*“...this is what we don’t know...each long term disability company is different and each policy is different...so the problem is we just don’t know what would happen...if long term does what we think they would do they would start me off on part time and working me into full time...so they would be supplementing my income slowly until I was back full time working and then they would cut me off...that’s the good scenario...the bad scenario is that long term contacts the work place, the work place says no we don’t want him back and long term says they don’t want you back, you’re on your own and cut you off.”*

The rules of government plans were confusing to some participants:

*“...I am on Canada Pension with a small ODSP...and I think they just changed the rules but up to recently if you worked at a volunteer work you were cut off...if I moved on to part time work, Canada Pension would cut me off and ODSP would say ‘if they (CanPens) don’t think he is disabled, we don’t either...’”*

Even understanding what qualifies for disability is conflictual:

*“My doctor said ‘you have clinical depression...we can put you on disability for that’...and I said you mean I am HIV positive and I can’t go on disability, but I can because I am sad about it...and he said ‘yes’.”*

One participant knew of others who were interested in returning to paid employment but were worried about not being able to get back on the disability pension coverage:

*“I know 5 or 6 people who would love to go back to work but they’re afraid to because the way the situation is now with the government...it’s almost impossible whether you’re HIV or not...you have to be almost dying before you can get back on ODSP or anything like that...so there’s a lot of fear about that.”*

However, another participant spoke of the flexibility of ODSP in relation to returning to paid employment and painted a different picture of support to return to paid work:

*“People don’t know that ODSP has a year where they can suspend your benefits...but you can be put right back on...so for the first year that I was working I was still on ODSP even though I wasn’t receiving money from them, so that I could still maintain my medications in case I was sick.”*

Uncertainty regarding the drug coverage under the Trillium program was identified by several participants:

*“...your number one concern when you’re ill is having your medications...and there isn’t an easy way of getting your medication unless you’re on some sort of government assistance...they have a thing called Trillium...”*

But the program is seen to have it’s problems:

*“...they have a new program called Trillium...if you have low income and high drug costs...you have to pay so much and then it starts kicking in...what I hear is horror stories...how it is way behind and you have to wait for the money... and where do you get the money in the first place...”*

Another participant commented:

*“I know somebody who got fired through their insurance plan when they found out that the insurance was going sky high...so there are different reasons why people don’t work...a lot of people don’t know about the Trillium program...they just think if I get a job, I wouldn’t get my coverage.”*

### Transformative Phase: Belonging (Containing Suffering)

Volunteers who were considering a return to paid work, turned to the ASO for assistance and guidance as a way of dealing with their confusion and conflict. Counseling was available through the ASO: through formal programs or individual counseling. Several participants went through “back to work” programs, or job readiness programs.

*“I went through the employment support program...they were going to help me find a job.”*

Another participant, however, recognized the opposite:

*“By the end of the course, I knew for a fact that, no, I could not go back to work right now. It would be too hard on me.”*

The volunteers recognized that there were people in the ASO who could support their efforts to return to paid work:

*“And a lot of people are there wanting to support you, to help you through this so, do it. You know, let them help you. You’ve helped others and now it’s your turn to receive back all that. And then by volunteering, well, you feel you’re giving something. Well, you’ve got talents.”*

*“They also insisted that I made the decision of - do I feel comfortable with that job and is it something that I really want to do. So they were trying to make sure that I was indeed in the right place.”*

Support was often described as “nurturing”, “advocating” and emotionally supportive:

*“So they work very closely and they nurtured me through that whole process.”*

And another:

*“They have been helping emotionally and also giving me ideas of what I could do”*

Job readiness programs and counseling were identified as helpful, but job readiness was always considered within the framework of not simply skills and ability, but also health:

*“Well they do all the normal job counseling but it’s also making you be realistic about how long does it take you to get up in the morning, when do you take your meds, how do*

*you eat, would you be comfortable talking in front of people or workplace, or how would you...And they're, they're really good about the all encompassing. But they also have all the information and they have the connections at \_\_\_\_\_ because the system is harsh and unfriendly and very threatening to people."*

One participant described the process:

*"What they do is sit down with people and do assessments with them to see if they're job ready, make you really look at your life to see if you're prepared to go back to work and really look at, you know, your health and your meds."*

Twelve volunteers in our sample had returned to paid work, eight of who were employed in an ASO. One participant revealed his enthusiasm for his new role:

*"How many positions are there available where you can talk about your meds or side effects or your viral load or things like that...and the gay folks can talk about what their gay lives are like and people with HIV can talk about that...so there's a comfort level that's a benefit...as beneficial as any benefits package..."*

One ASO worker, former volunteer, noted that there are beginnings of change regarding returning to work:

*"...but right now we have a lot of our clients that went back to work and to school. So, it is happening. We see it in the movement. And the new ones, it is easier because..."*

The opportunity to network either informally or formally was provided by the ASO:

*"And they gave my name, and they called me and I said "well, I don't know if I have the skills." They said "send us your resume and, we'll see if we'll grant you an interview." Which they did. And there were seven candidates and I got it?"*

Several participants took the informal route to network as a volunteer:

*"And I approached a friend of (name) who is in the same business, and she kind of guided me a little bit with the resources and what has to be done and so forth."*

*"So what happened was that my friend, at the time, was in the middle of buying a company. So he told me about it. One day he just called me and he said to me, are you ready to go back to work? And I said to him, I have been ready for a long time."*

As the participants tried to contain their suffering there were many hurdles to overcome.

Some of these hurdles had to do with the "self":

*“...there are times where I wake up in the morning, look in the mirror and then talk to me and my virus or my illness and say, ‘I have this work ahead of me - today I must do this...give me the energy to do that and I promise I will take it easy the next day...’ anybody will say no...not a day to do this...put it off - so I negotiate with myself.”*

Other hurdles had to do with dealing with the bureaucracy and “navigating the system”.

One participant learned of a way that was successful for him/her in getting the help he/she needed:

*“By putting - ‘willing to attempt to go back to work with rehabilitation’ - that means that the insurance company has to get involved, they have to interview the employer, see if they can fit you into a job, maybe start you off on part time, work you into full time over 6 months. They have to be involved in trying to get you back to work because you’re, you’re saying I’m willing to attempt it, I’m not sure that I’m going to be successful.”*

Sometimes, it was others who “planted the idea” to return to work. Two participants suggested the role of physicians in influencing their decision to actively pursue the possibility of returning to work:

*“About 2 months ago now I got a review from my long-term disability, which of course I get a review from every year, and the doctor said to me, it’s maybe time you think about maybe going back to work full time.”*

*“He planted that idea and to be honest we’ve had a few friends over the last maybe 2 years that have actually gone back to employers. Now their employers have been very work friendly and very supportive. Some of them have gone back to work part time and long-term.”*

Staff and other volunteers at the ASO had a role in empowering others: “You are capable of working”. As another participant noted:

*“It’s because of those who taught me these skills and gave me the push to go and further myself.”*

A major hurdle had to do with establishing an “understanding” work environment and supportive employer. Several participants felt the workplace needed to be better educated about

HIV/AIDS, homosexuality and how HIV/AIDS is transmitted for successful re-entry to the workforce of those who are HIV positive. As one participant identified:

*“The work environments try to deal with homophobia, try to deal with racism. HIV conjures up so much fear in people and I don’t think enough has been done to date to deal with that in the workplace and therefore it’s going to make it that much harder for people with HIV to make the conscious decision to go back.”*

Another participant thought:

*“...best thing to do is first help educate the workplaces on how to deal with people who not only have HIV, but are dealing with any illness, but HIV in particular because it is considered a transmissible but not through a work environment or anything...it just isn’t going to happen.”*

One participant summarized succinctly:

*“You have to have a work environment that understands.”*

#### Transformative Phase: Becoming (Transforming Suffering)

The transformative phase of “becoming” represents a reappraisal of the way life is lived and a recognition of a new purpose in life. Participants spoke of starting to dream and this was expressed in many ways:

*“Well I’m starting to dream and I haven’t dreamt in so long that it’s, it’s all new.”*

Or another:

*“...you know maybe I’m dreaming but I’m also to the point now where I’m thinking - why not dream, why not, why not reach for the stars and see what happens?”*

For another participant:

*“...I’m not supposed to be here...they kept telling me I wouldn’t see the year 2000...I’ve gotten beyond that now and I’m starting to dream.”*

One participant in starting to dream of a different future noted:

*“It’s exciting but it’s also a little scary sometimes.”*

It appeared from the narratives, the choice to “move on” to active daily living in paid or unpaid work; the choice to be involved with others and give of the self and the freeing of the self from the “little box of disability” was a major liberating experience:

*“...if you get to the year 2000, you’re going to be lucky...now my doctor is saying ‘so in 20 years time what do you see yourself doing?’...and I’m like 20 years! I spent so much time confining myself to this little box of disability... this is who I am...this is what I can do...and now maybe the box doesn’t exist anymore and what are the limitations that I can do right now...”*

There seemed to be moments of clarity and self awareness that became turning points in the choice to move forward:

*“If I’m going to get sick and die, I’d rather do it doing something I’m enjoying. And you know in 20 years time, I want to be able to look back and say, I always wanted to do this and I did it as opposed to, ‘God, you know, I wish I had of...’.”*

Even though the pain continued, one participant reached the recognition of his/her need to move beyond the pain:

*“And I was also living with the pain...but I just didn’t care. I just wanted to get out and get on with my life.”*

Recognizing the “gift of life” and being “the best that you could be” was important for one participant:

*“Every day is a gift. You get up and you do what you can to be the best that you can be.”*

Another participant used the metaphor of a book:

*“And I just keep moving on. I just try and keep turning the pages.”*

It was clear from the narratives that each participant had to choose what was meaningful for each from his/her own perspective. For one participant, it was the realization that he/she could not change his/her HIV status but he/she could still find meaning in life:

*“I guess it’s because I got to the point where I’m not going to get hung up on this, there’s nothing I can do to change it. At that point I was not well, I cannot work. If I do work, I will get sick and I will die. So it’s not, it’s just not an issue.”*

Another participant recalled a turning point:

*“But I got to the point where I’ve moved on from, from having to define myself by work and I moved on from that. Not that I disclosed my status to everyone, what I was doing to everyone, but I sort of moved on from that. And I have a lot of friends who haven’t been able to. They still feel guilty because they can’t work.”*

Another participant realized his need to redefine himself in relation to work:

*“And I’m going to redefine myself by other things. I’m going to volunteer. I’m going to do...and this is who I am now as opposed to, to describing myself as a work thing.”*

Finding meaning in doing what you can do, or finding a passion is a recognized need.

The participants realized that finding meaning in activity was the most important thing - not whether it was paid work or volunteer work:

*“And he hasn’t been able to find meaning in volunteering and meaning in life in other ways. I don’t know. I guess I’m just, I’ve always had a very positive view of life.”*

For another participant:

*“Absolutely felt called out to do it, right? Felt it was a vocational thing as much as anything else. And part of that is the integrity of work of the agency, the value of the work itself, the fact that it is for me meaningful work, that it connects to me beyond just a paycheck. And in fact if you were using the paycheck (laughs) as a measuring stick, I wouldn’t be here. You wouldn’t be doing AIDS work.”*

*“It is my passion, it is not my work”*

This participant articulated the struggle most clearly and he will be given the final word:

*“I would love to see other people have an easier time of, of it than I did, especially going on, on long-term disability and finding meaning in life and, and things like that. I don’t know that...I think it’s everybody’s own journey. I think they have to go through it themselves.”*

It is truly everyone’s own journey.

## **Discussion**

Hall (Hall, 2001) conceptualized a process of bearing witness to suffering in HIV/AIDS as the construction of meaning from loss. He identified 3 stages: experiencing suffering, containing suffering, and transforming suffering. Our conceptualizations recognize the ongoing processes involved in the transformation of meaning which we described as being, belonging and becoming. However, we grouped these transformations within the context (events) in which they occurred.

We thought to understand the stories participants told us within the context of the transitional events they identified as key periods in their lives after hearing the diagnosis of a positive HIV status. We developed a model that could capture their words and thoughts. The model we suggest implies movement through 3 different phases, which we described as being, belonging and becoming, toward an illusive something, not fully defined but best described as self actualization, or self growth (Maslow, 1954),(Alderfer, 1969). The model, however, is not simply linear or hierarchical. Rather, the model remains dynamic and circular, returning to earlier phases when the threat to “being” needs to be confronted and contained again. We assume, however, that a person can be working on a growth need even though being or belonging needs are unsatisfied.

Our understanding of the first phase, what we have labeled “being”, represents a challenge to deal with and control two basic human needs participants identified: survival and security. These needs are always present but demand more or less attention at different periods. It is when these needs can be contained that the individual can more readily recognize the need to “move on”. Participants spoke of “moving on”, “getting on with it”, making choices and reaching out toward others - the need to “belong in the world” outside of the self. In this phase

of “belonging”, participants began to take control of their own destiny by looking at themselves as a whole and in relationship with others.

The third transformational phase, we describe as “becoming”. In this phase, participants took the opportunity to grow and enhance the meaning of their lives for themselves. Each participant became the source of his/her own potential, recognized the need to be aware of him/herself and be responsible for him/herself.

Being, belonging and becoming are participles describes someone in the process of being something, whose choice is to give meaning, value and purpose to his/her life. As one participant said:

*“I would love to see other people have an easier time of, of it than I did...and finding meaning in life and things like that...I think it is everybody’s own journey. I think they have to go through it themselves.”*

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# **APPENDIX A**

## **Interview Guide**

## Appendix A

<p>Interview Guide Individuals Who Have Moved from Client to Volunteer to Paid Worker</p>
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We are interested in the transitions people move through when they move from being a client to a volunteer and then again from a volunteer to work with pay. The following questions are to guide our discussion but to feel free to add any additional comments you may have.

1. When you think back to the time before you were a volunteer, what do you think made you want to volunteer?
2. Can you tell me what it was like for you as a volunteer?

### **PROBES:**

What kind of work did you do? Did you work directly with clients? Behind the scenes? Learn new skills?

Did this fit in with what you felt you had to offer / what you wanted to do as a volunteer?

How did the organization help you to get involved?

What sorts of things helped in the transition from client to volunteer?

3. In thinking back to when you were a volunteer, what were:
  - a) some of the skills you developed?
  - b) rewards of the role?
  - c) difficulties you faced? Stresses?
4. Some clients/volunteers decide to make the move to a more formal paid arrangement. We're really interested in trying to understand this process, what's involved in that decision, why some people do and why some don't. Do you have any ideas on this?

## **APPENDIX B**

### **Information and Consent Form for Interviews**

**Appendix B**

**Information and Consent Form for Interviews**

The Community-Based AIDS Service Evaluation (CLEAR) Unit is doing a study on the needs of ASOs in the areas of recruitment, retention and deployment of staff and volunteers.

Interviewers from the CLEAR Unit would like to ask you about your working environment, your motivation for working/volunteering in the ASO, and the skills you think are necessary for you to have to work as a volunteer here. The interview should take about one hour. If you give permission, the ASO will give your name and phone number to the interviewers from the CLEAR Unit so that they can call you for an interview. We know you will find the questions thought provoking and interesting. Your responses are important to us.

YOU DO NOT HAVE TO TAKE PART IN THE STUDY. THE ASO WILL NOT KNOW WHETHER YOU PARTICIPATED OR NOT. YOUR PARTICIPATION IN THIS INTER= DOES NOT AFFECT ANY SERVICES YOU PRESENTLY PROVIDE OR RECEIVE FROM THE ASO. YOU MAY AT ANY TIME CHOOSE TO STOP THE INTERVIEW. ALL INFORMATION YOU GIVE IS CONFIDENTIAL. YOUR NAME WILL NOT BE CONNECTED TO ANY OF YOUR ANSWERS. THE ASO WILL NOT GIVE ANY OTHER INFORMATION ABOUT YOU TO THE CLEAR UNIT AND THE CLEAR UNIT WILL NOT GIVE ANY INDIVIDUAL INFORMATION TO THE ASO. THE RESULTS OF THE STUDY WILL BE MADE AVAILABLE TO THE ASO AND PRESENTED IN GROUPED FORM (THAT IS, NO INDIVIDUAL WILL BE IDENTIFIED).

If you have any further questions about the study, you may call Joan Crook (collect) at McMaster University (905) 525-9140 Ext. 22298.

The study will take about six months to complete. If you are interested in receiving the results of the study, you may call the phone number above.

\* \* \* \* \*

Yes, I agree to participate in an interview.

Signature \_\_\_\_\_

Print Name \_\_\_\_\_

Phone # \_\_\_\_\_

Address \_\_\_\_\_

Postal Code \_\_\_\_\_

Witness \_\_\_\_\_

Date \_\_\_\_\_, 2000

Other Contact \_\_\_\_\_

## **APPENDIX C**

### **Constructing Meaning from Transitions Coding Categories**

## Appendix C

### **Constructing Meaning from Transitions Coding Categories**

#### **Receiving a Diagnosis (DX)**

\$Dealing with dx with self

\$Dealing with dx with others

\$Finding supports

#### **Leaving Work**

\$Previous job

\$How people responded at work

\$Reasons for leaving

\$Life without work

#### **Volunteering**

\$Previous life experiences → influencing decision to volunteer

\$Reasons for volunteering

\$What they get from volunteering - Positive effects

\$Support received as a volunteer

\$Negative aspects of volunteering

#### **Returning to Work**

\$Worries about returning to work

\$losing meds

\$how will be treated

\$unpredictability of illness

\$Assistance in returning to work

\$Education in work places

\$Positive effects of work

## **APPENDIX D**

### **Constructing Meaning from Transitions The Transformative Process**

**Appendix D**

**Constructing Meaning from Transitions  
The Transformative Process**

**Transitional Event: Receiving a Diagnosis**

<b>Being (Experiencing Suffering)</b>	<b>Belonging (Containing Suffering)</b>	<b>Becoming (Transforming Suffering)</b>
<b>Experiencing Loss</b> <b>Major Life Event;</b> Life crisis Untimeliness (stage of life) Disbelief  <b>Chaos: Multiple Losses and Challenges</b>  Overwhelming fears Facing losses Stigma and shame Lowered self esteem I am my disease	<b>Confronting Loss/Establishing Control</b>  <b>I Am More Than My Disease;</b>  Taking control Determining what is important in life  <b>I Need Help;</b>  Finding support/establishing relationships	<b>Recognizing Purpose in Life</b>  Moving on Leaving a legacy Redefining priorities
 <b>Transformative Process</b>		

**Appendix D**

**Constructing Meaning from Transitions  
The Transformative Process**

**Transitional Event: Leaving Work**

<b>Being (Experiencing Suffering)</b>	<b>Belonging (Containing Suffering)</b>	<b>Becoming (Transforming Suffering)</b>
<p><b>Experiencing Loss</b></p> <p>Keeping the secret</p> <p>Losses in the workplace (rights; benefits, trust, identity, physical strength, meaning of work, independence)</p> <p>Anticipated future - uncertainty</p> <p>Deteriorating health</p> <p>Catch 22</p> <ul style="list-style-type: none"> <li>- treatment options</li> <li>- benefit options</li> </ul> <p><b>Life Without Work</b></p> <p>Poverty</p> <p>Rules of the benefits game</p> <p>Loss of relationships/identity/isolation</p>	<p><b>Confronting Loss/Establishing Control</b></p> <p>Benefits of leaving</p> <p>(Decreased stress in life; and improved health)</p> <p>Finding self</p>	<p><b>Recognizing Purpose in Life</b></p> <p>It's not just about me any more.</p>
<p>← <b>Transformative Process</b> →</p>		

**Appendix D**

**Constructing Meaning from Transitions  
The Transformative Process**

**Transitional Event: Volunteering**

<b>Being (Experiencing Suffering)</b>	<b>Belonging (Containing Suffering)</b>	<b>Becoming (Transforming Suffering)</b>
<b>Experiencing Loss</b> Loss of relationships	<b>Confronting Loss/Establishing Control</b> Develop meaning and purpose Self development/personal growth Paralleling Previous Life Experiences - social justice - social circumstances - service orientation Rewards/benefits - stability - life enrichment Belonging and affiliation	<b>Recognizing Purpose in Life</b> Personal values enhanced Part of upbringing Self-competency
 <b>Transformative Process</b>		

**Appendix D**

**Constructing Meaning from Transitions  
The Transformative Process**

**Transitional Event: Returning To Work**

<b>Being (Experiencing Suffering)</b>	<b>Belonging (Containing Suffering)</b>	<b>Becoming (Transforming Suffering)</b>
<p><b>Experiencing Loss</b></p> <p><b>Worries About Returning to Work</b></p> <p>Loss of benefits            About how treated in the workplace            About illness uncertainty            About medications            About work force absence</p>	<p><b>Confronting Loss/Establishing Control</b></p> <p>Assistance in returning to work</p> <p>Networking            Mentoring            Skills learning            ASO counseling            Taking courses            Job readiness            Dealing with bureaucracy            Empowerment            Employer support</p> <p>Education in Work Places</p>	<p><b>Recognizing Purpose in Life</b></p> <p>Starting to dream</p> <p>Finding new meaning in life</p>
<p align="center">    <b>Transformative Process</b> </p>		