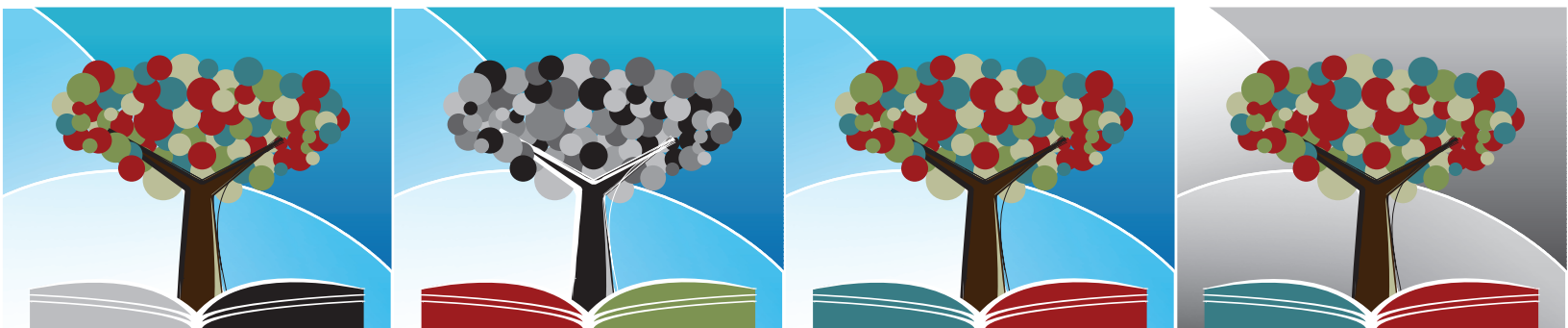


K N O W L E D G E   D E V E L O P M E N T   C E N T R E



# Volunteering by People Living with HIV/AIDS or a Major Chronic Disease: Issues and Challenges

A Research Report

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The logo for Canada, featuring the word "Canada" in a serif font with a small maple leaf icon above the letter "a".

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# Volunteering by People Living with HIV/AIDS or a Major Chronic Disease: Issues and Challenges

## Introduction

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This research had two purposes, first to document the contribution made by volunteers living with HIV, second to study how these individuals are accepted by various nonprofit organizations in the Toronto area. In other words, this study seeks to understand the importance of volunteering for these individuals and how well they are accepted when they volunteer their services.

These two objectives fall within a context where people living with HIV now have a significantly improved life expectancy and quality of life. Thanks to medical advances, HIV is now considered a chronic disease that develops over a long period of time. Nevertheless, there continues to be a strong and painful social stigma attached to HIV.

Clearly, the state of health enjoyed by most people living with HIV today allows them to be reasonably active. In this sense, volunteering may appear to be a type of activity well suited to their condition and be particularly valuable. However, one wonders whether the stigma attached to HIV can adversely affect their reintegration into society.

We first discuss the new reality as it pertains to HIV and major chronic diseases as a whole, to present have a clear understanding of how the life of affected individuals has been vastly improved thanks to the new developments in the medical field. We then examine how one can learn to live with HIV as a chronic disease and the related issues, while emphasizing the importance of social support.

In Section 3, we address the research methodology. In Section 4, we introduce the themes identified during the data analysis and, finally, we discuss the specific contribution of the research and the resulting recommendations.

Due to confidentiality considerations, we cannot provide all the characteristics of our informants. If we do so, they would be easily recognizable within the small community that comprises volunteers with HIV/AIDS.

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## 1. The new face of HIV/AIDS and major chronic diseases in Canada

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Medical science has advanced by leaps and bounds in the last twenty years. Many diseases that had previously been considered fatal at a relatively early stage have gradually become chronic diseases that evolve over a long period of time. HIV/AIDS is probably the best case in point. Until 1995, being diagnosed with an HIV infection was equal to being handed a death sentence. This is no longer the case. With the development of antiretroviral therapies, the mortality rate of infected individuals has dropped dramatically. When the first antiretroviral agents were introduced in 1995, 1,493 Canadians died of HIV/AIDS; in 2002, the number of deaths dropped to 89 (Health Canada, 2003). Therefore, HIV-infected individuals are today living both better and longer (Argentier, Fernet, Lévy, Bastien, et Fernet, 2003).

However, HIV/AIDS is not the only disease to benefit from the positive effects of the advances being made in the medical and pharmaceutical sciences. Other major chronic diseases can now be treated relatively successfully. Cancer is a good example. According to data from Statistics Canada (2004), the number of cancer-related deaths has steadily decreased since 1984 (Table 1, p.3). More specifically, in 1984, the death rate for Canadians diagnosed with cancer was 247.83 per 100,000. In 2001, the number of deaths had dropped to 224 per 100,000. The survival rate today of people diagnosed with cancer is 51%, i.e. these individuals will not develop any new symptoms over a five-year period.

The same holds true for cardiovascular diseases. While cardiovascular disease remains the number one cause of death in Canada (Table 2, p.3), new advances in surgical, medical and pharmacological therapies have significantly improved the situation of people living with a heart condition (Table 3, p.3).

In conclusion, individuals living with a major chronic disease today are living better and longer than in the past. Since 1984, the death rate has gradually decreased (Table 3, p.3), thereby changing the face of chronic diseases in Canada.

**Table 1: Death rate from cancer (per 100,000).**

	1984	1985	1986	1987	1988	1989	1990	1991	1992
<i>Rate/100,000</i>	247.83	248.97	248.99	248.22	254.74	249.54	246.47	247.17	244.69
	1993	1994	1995	1996	1997	1998	1999	2000	2001
<i>Rate/100,000</i>	242.75	241.81	238.94	236.50	232.27	230.50	229.40	225.39	224.00

**Table 2: Deaths from cardiovascular diseases (per 100,000).**

	1985	1986	1987	1988	1989	1990	1991	1992
<i>Death/100,000</i>	303.79	303.66	294.03	292.49	284.62	271.07	271.25	268.56
	1993	1994	1995	1996	1997	1998	1999	
<i>Death/100,000</i>	274.86	270.60	269.50	267.76	268.14	262.49	258.83	

**Table 3: Deaths due to major chronic diseases over time, all causes.**

	1984	1985	1986	1987	1988	1989	1990	1991	1992
<i>Rate/100,000</i>	792.74	798.43	789.12	767.87	769.41	748.62	728.43	720.44	706.06
	1993	1994	1995	1996	1997	1998	1999	2000	2001
<i>Rate/100,000</i>	717.72	707.66	702.70	692.40	683.54	674.51	662.19	636.40	622.38

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## 2. The importance of adjusting

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Being diagnosed with a chronic disease is no longer necessarily synonymous with a death sentence. Quite the contrary, the affected individual must now learn to live with a disease that develops over time, and to integrate it into his or her daily life. In some measure it means acquiring a new sense of normalcy where life goes on, but differently. Surprisingly, individuals diagnosed with a chronic disease often develop, over the course of the adjusting process, a deeper sense of fulfillment with regard to life than they had before their diagnosis (Samson, 2006).

In order to regain a certain sense of happiness and accomplishment, it is critical for the individual affected to rebuild his or her life. The effort invested into this rebuilding process varies greatly from one person to the next and, quite frequently, the appearance of the disease has a devastating effect. In addition to having to develop new life habits, the individual must learn to control the impact of the disease.

For example, this new way of living generally involves taking medication on a regular basis, accepting the physical limitations inflicted by the disease, and being under fairly regular medical care. Ideally, the person affected by the disease must try to maintain the right emotional balance and find a new meaning to his or her life. All this leads to having a new appetite for life (Cohen et Lazarus, 1978; Moos et Stu, 1977; Corr, 1993).

Seeking solid social support is certainly one of the keys to adjusting to the disease. It is when the disease first strikes that an individual most needs a warm environment, the ability to talk about his or her suffering and to share his or her fears. But while the disease triggers the desire to seek the company of others, it can also represent the main barrier to satisfying that same desire. Indeed, the disease often confers upon the affected individual a sort of marginal status that can cut him or her off from his or her usual network of contacts. Its appearance often means the end of a certain way of being that underlies the maintenance and development of interpersonal relationships. The disease often causes an individual to adopt a different pace of life making it difficult, if not impossible, to maintain a steady relationship with others (Corr, Nabe et Corr, 2003).

In addition, the disease may also stir up feelings of fear and apprehension of death and suffering among loved ones, so much so that the affected person might feel abandoned, let alone rejected, because his or her very presence is a constant reminder of mortality, which the others do not easily accept.

Finally, social stigma can be attached to the disease. The HIV infection is a good example of this. Infected individuals are still often perceived as lepers and some must resign themselves to practically living in hiding in order to avoid the intolerance of those around them.



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In conclusion, the appearance of a disease can lead to some sort of social death. Indeed, a disease can cause an individual to be excluded just when he or she most needs solid support, an attentive ear and warm companionship in order to overcome it. There are several ways to ensure a fulfilling social life. Belonging to a support group made up of one's peers is an excellent form of social support. Individuals living with HIV who have access to such a support group can derive many benefits from it. This type of support helps to break isolation, to build bridges with the medical community and to fight against discrimination.

Having the support of others represents both a need and a challenge, and this is particularly true for HIV-infected people. Because of the huge stigma attached to HIV, the infected individual may be tempted to keep his or her disease a secret, thereby denying himself or herself the support he or she needs throughout the course of the disease.

The challenge is often revealing one's HIV status because the possibility of rejection is always present. If the individual can overcome this fear, he or she will be able to benefit from the support of others. For HIV-infected individuals, appropriate social support goes hand in hand with increased self-esteem and a lower risk of depression.

As we have seen, the appearance of a disease can negatively affect one's social network, including a temporary or permanent withdrawal from the labour force. However, the need to withdraw from the workforce does not necessarily signify the end of a career. In fact, according to Riverin-Simard (2002), a career goes beyond the realm of paid activities since it covers any activity performed within the community, including volunteering.

It is therefore important to emphasize that a person living with a chronic disease can always have a career even if he or she has stopped working. Indeed, a career represents for most people the preferred way of expressing themselves, of creating and developing their identity, of integrating into society and of interacting with others. The appearance of the disease does not necessarily remove one's ambition to invest oneself in a career path. Returning to some form of activity can even be set as an objective, given the fact that advances in the medical field are increasing the life expectancy of affected people and improving their quality of life. For many of them, resuming sustained involvement in social life is a realistic and even desirable possibility.

It must be emphasized that HIV-infected people feel particularly strong about resuming a career path (Ferrier et Lavis, 2003). For these individuals, a career keeps them connected to the outside world and brings structure to their everyday life. Thus, instead of simply returning to the job market, for these people volunteering often represents a better option. There are several reasons for this.

First, from a medical perspective, volunteering allows a certain flexibility that a gainful occupation does not necessarily provide. In fact, living with HIV or some other chronic disease implies the need to take medication, having lower physical and psychological stamina and requiring medical supervision. Managing a major chronic disease requires both time and effort. In many cases, volunteering is the only activity to provide the opportunity to manage the disease while maintaining an active lifestyle (Samson, 2006).

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### 3. Methodology and purpose of the research

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The context of this research is one where individuals living with HIV or another major chronic disease enjoy a longer life expectancy and a better quality of life. A number of these individuals decide to offer their services to voluntary and nonprofit organizations. The purpose of this study was to gain a better understanding of their real-life experience as volunteers. To this end we asked them several questions.

#### Questions for people involved in volunteering

1. Please describe the current volunteering activities in which you are involved.
2. What motivates you to become involved in a voluntary or nonprofit organization?
3. What importance does volunteering hold in your life?
4. How do you benefit, as an individual, from your volunteering activities? Socially? Professionally? In terms of your personal development?
5. What meaning does your volunteering hold for you?
6. Is it because of your HIV infection that you became involved with a voluntary or nonprofit organization?
7. How do you reconcile the medical implications of your HIV infection with the duties of your volunteering activities?
8. Are you openly living your HIV status in the voluntary or nonprofit organization in which you are currently involved? If so, why? If not, why not?
9. Do you think that the voluntary or nonprofit organization in which you are involved has an open and friendly attitude towards people living with HIV? If so, why? If not, why not?
10. Do you sense some sort of rejection of people living with HIV on the part of some of the people working in your voluntary organization?
11. Do you know whether the voluntary or nonprofit organization in which you volunteer is looking to recruit people living with HIV? If so, what do you think of such an initiative? Please explain. If not, do you think it should? Please explain.
12. In your opinion, what barriers might prevent people living with HIV from volunteering? Have you noticed any of these barriers in the voluntary or nonprofit organization in which you are currently working?
13. In your opinion, what might motivate a person living with HIV to join a voluntary or nonprofit organization?
14. In your opinion, what enhancements could the voluntary organization in which you are volunteering make to promote volunteering among people living with HIV?

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The purpose of this questionnaire was to get the participant to describe his or her volunteering activities as completely as possible. Subsequently, the purpose was to gather as much data as possible for analytical purposes. To this end, the testimonies of all twelve individuals were recorded and then analyzed according to a qualitative data analysis methodology. The purpose of this analysis was to identify and describe the major issues emerging from their testimonies as a whole, in order to gain a better understanding of what volunteering brings to their everyday life.

The participants were recruited in the Ottawa-Gatineau and Toronto areas. They had to be able to express themselves in French and to have been diagnosed with HIV. Considering the social stigma attached to these individuals, the recruiting process can be problematic. For this reason, we used various means to identify the individuals who might be interested in our research project. Therefore, the subjects were recruited by means of an advertising campaign targeting organizations involved with people living with HIV, as well as through word of mouth.

All the participants were homosexual males. We realize that this sampling is neither representative of the homosexual female segment nor of heterosexuals also living with HIV. This is probably an indication that the stigma attached to HIV causes those living with HIV to live in isolation. We must specify that our first intention was to recruit subjects of both sexes and with different sexual orientations.

For their part, the participating organizations had to serve a diverse Francophone population. By diverse we mean that the services they offered were not restricted to the population living with HIV. We identified organizations in the Toronto area that were fairly well established within the community. We selected organizations with paid employees, that had been incorporated for at least two years and that were receiving subsidies from various levels of government. Of course, these organizations also had to rely on the contribution of volunteers to achieve their mission.

Of the six organizations we contacted, we considered the testimonies of five voluntary organization managers. The missions of the organizations surveyed had very different areas of focus, such as communications, health services, pressure groups or public education services. The managers were each invited to answer a questionnaire. Their testimonies were recorded and subsequently transcribed.

## Questions for voluntary organization managers

1. What is the mission of your voluntary organization?
2. Are you aware whether any people living with HIV are working in your organization? If not, why not? If so, how did you find out?
3. Has your organization actively tried to recruit people living with HIV? If so, please describe this experience and its results. If not, why not?
4. Has your organization developed an outreach policy for welcoming and integrating individuals living with HIV who have expressed their wish to volunteer in your organization? If so, could you describe this policy? If not, why has such a policy not been implemented?
5. Do you believe that a volunteer who is openly living with HIV would feel comfortable in your organization? If so, why? If not, why not? Do you have any concrete examples to back this up: i.e. do you have members who are openly living with HIV?
6. Do you believe that your organization should try harder to recruit volunteers living with HIV? Do you believe that your organization is ready for such a move (if this is not already the case)?
7. Do you feel that your organization provides an environment where people living with HIV can feel comfortable? In your opinion, are there any factors that could make the integration process any easier? Are there any factors, in your opinion, that slow down or hinder the acceptance and integration of such individuals?

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## 4. Themes

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Six themes were identified through the qualitative analysis of the participants' testimonies. In other words, we were able to identify common threads throughout these testimonies. The purpose of this analytical process was to understand the different experiences in order to arrive at a description that reflected as accurately as possible the various components of the volunteering experience for the participants. The six themes identified are:

1. volunteering gives life a new meaning,
2. volunteering enhances one's self-image,
3. volunteering helps in social reintegration,
4. volunteering provides time structure,
5. volunteering is a form of self-expression,
6. volunteering breaks down the wall of secrecy.

With respect to nonprofit organizations, the qualitative analysis of the managers' testimonies raised two main themes relating to the inclusion of people living with HIV/AIDS. The first theme focuses on the values held by these organizations. The organizations surveyed all adhere to values of inclusion that exclude all forms of discrimination. However, the second theme raises the fact that these nonprofit organizations do not factor in the components of the HIV/AIDS issue in order to include persons living with the virus.

### 4.1 Themes identified from testimonies of people living with HIV

#### ***Theme 1: Volunteering gives life a new meaning***

Being diagnosed with HIV triggered a life crisis for those who participated in the study. This diagnosis is associated with death and puts an end to a certain lifestyle or way of being. For example, from a medical perspective, the stricken individual must learn to live with a potentially fatal disease that has an uncertain course and that makes it necessary to be under medical care and to take medication on a constant basis. In addition, HIV isolates and stigmatizes. All in all, as evidenced in the testimonies, life loses its meaning and coherence because the affected individual is directly faced with his or her mortality.

For the subjects who took part in this research, volunteering is a way of providing a new dynamic in their lives. In other words, the participants experience a new form of internal coherence built around their volunteering experience. In a way, volunteering becomes a centre of gravity that organizes their life and gives it direction.

Now that their life has been given new meaning, these volunteers regain a sense of usefulness because they can contribute to society and become actively involved in social life. In other words, the individual once again feels like a full time citizen and rediscovers a sense of purpose.

*“In terms of my life, this is very important, it’s an integral part of my life...It’s the reason why I’m still alive. It is a reason to live, to continue to change, to evolve. For me, for myself, for my growth, this is critical, it keeps me alive.”*

*“I seriously questioned myself. I told myself that I was good for something. I can still be useful. Do something I like.”*

*“At first, I associated the infection with death, I was facing a wall, volunteering opened a door for me and I discovered that life was still possible.”*

*“Volunteering is directly connected to the meaning of my life. My volunteering activities are a way for me to fulfill my mission in life...Helping others, this is a very meaningful aspect of my mission. Volunteering expresses my mission in life.”*

## **Theme 2: Volunteering enhances one’s self-image**

According to the testimonies of participants, the HIV infection destroys, to a certain extent, their self-image or self-perception. Generally, the affected person feels diminished not only because the infection threatens his or her physical integrity, but also because it is clear that society invariably attaches a heavy stigma to those who are infected.

For all these reasons, the participants developed a relatively negative image of themselves. They perceived and continue to perceive themselves as diminished individuals who have lost part of their dignity and their fundamental worth. In other words, because of the condition from which they are suffering, the participants see themselves as “toxic lepers.” They have lived and sometimes continue to live their disease as a deep and painful wound that has devastated their self-image.

According to the participants’ testimonies, volunteering helps them to enhance their self-image. Volunteering provides a place where a person can learn to develop a self-image that is unaffected by the negative influence of surrounding prejudices. It also provides an environment free of any social stigma where the affected person can rebuild a more positive self-image.

In other words, volunteering provides a shelter where participants can be themselves without fear of being rejected because of their HIV status. This allows the individual once again to express himself or herself, to become committed, and to grow on a human level by doing something useful and unselfish. This individual regains his or her self-confidence, rediscovers the ability to be friendly and learns that others do care.

Volunteering also helps the participants to enhance their self-image, because their commitment is also a way in which they can seek new challenges and rediscover their personal skills while developing new ones. They are finally able to perceive themselves under a new light; instead of receiving care and feeling dependent, they develop a sense of usefulness and reciprocity, thanks to their volunteering activities. They feel better.

### **Theme 3: Volunteering helps in social reintegration**

All of the participants find it hard to accept the social stigma that was and continues to be attached to those living with HIV. They feel judged and rejected. Most of them hide their condition and only tell their loved ones or people they feel they can trust about their HIV status. Participants perceive themselves as victims of bias and of ignorance within their society.

This secrecy leaves them feeling as if they have lost their dignity and their intrinsic self-worth. The rejection is a source of lingering moral suffering which adds to the torment of living with a potentially fatal infection whose course is uncertain.

The participants feel lonely and sometimes even abandoned. At times the feeling of being shunned throws them into a state of shame and embarrassment. This is even harder to bear since, as people living with HIV, they crave even more the need to be heard, to talk and to feel understood and accepted.

In such a climate the participants view their volunteering as a lifeline. For many of them, volunteering represents the only real way of building

*“It lets me play a role in my community, otherwise I would be totally dependent on others.”*

*“For me as a person, my volunteering activities make me feel more important, they feed my self-image. After many losses, I felt like I couldn’t do anything anymore. But, being a volunteer is very satisfying because I can continue to be productive. I am doing something worthwhile of which I can be proud. I feel diminished by the disease, but I am still capable of doing something useful.”*

*“I feel appreciated by others. This makes me happy. Volunteering has given me a certain inner peace...I give to others and I feel that what I do is appreciated...It gives me hope that I can make a difference.”*

*“It’s a way to achieve self-fulfillment...”*

*“I no longer feel dependent on society... I feel useful, like I am sharing the wealth and that is important. Volunteering validates my self-worth. It helps me strengthen and maintain a positive image...”*

bridges, creating links or just simply enjoying the company of others. Also, most participants say that they prefer working mostly for nonprofit organizations providing services to people living with HIV or who are homosexual. This preference stems from the fact that the participants want to work within organizations where they can openly live their HIV status without fear of being rejected or shunned.



More specifically, volunteering is a way for the participants to rebuild their interpersonal relationship network or at the very least to expand it. It is also a way for them to meet new people who are also facing the challenge of living with HIV. Sharing the same experience gives them the assurance that they are understood and the opportunity to open up without fear of rejection. Meeting new people also provides an opportunity for learning.

Therefore, volunteering provides a very special type of support. This is particularly important and it lends a very special value to volunteering. Not only does volunteering help put an end to isolation, but the participants often also discover a true community life where they can grow.

*“Volunteering allows me to have some very touching encounters that I find very rewarding. These encounters give me the energy I need to go on living.”*

*“Socially, volunteering helps me develop new relationships, new friendships. The network is smaller but just as rich. I meet people who are facing challenges just as big as mine, life issues such as suffering, disease, loss. I recognize myself in people who are having to deal with the same critical issues as I do. There is also the opportunity to share emotions or life experiences. I am living a social dimension which ordinary workplaces could not offer me.”*

*“Socially, I need to be with people, to work with others, and to pursue objectives with others.”*

*“I therefore decided to reveal my HIV status in a place where I would not feel rejected, where there would be no risk, a comfort zone. The place makes all the difference. If I feel accepted, I don't feel stressed. When you have HIV, low stress is a must.”*



#### ***Theme 4: Volunteering breaks down the wall of secrecy***

For participants, the stigma attached to those who are living with HIV is often harder to take than living with the infection itself. The rejection, the disgrace, the prejudices and the shunning often cause deep mental distress which feeds a tenacious and persistent inner pain. Revealing that one is HIV-infected can therefore be a risky proposition requiring strong courage and rather long deliberation. To avoid rejection, it is important to identify the people and the environments that are most apt to accept such individuals openly, and with respect and compassion.

If social rejection often imposes on the participants the need for some form of secrecy and accommodation, these volunteers find it impossible to endure the stigma or the weight of such a heavy secret. This is why the participants much prefer to work for voluntary organizations that specialize in providing services to HIV-infected people or homosexuals.

*“Homosexuality is very taboo, very controversial. People say that things are now much more open. I’m not so sure. Deep down, the rejection and the threat still exist. The risk of exclusion is always there...”*

*“I realized very early on that I could not offer my services as a volunteer just anywhere, you just feel that people living with HIV are not welcomed everywhere. That’s the reality. Therefore, I decided to work in a place where I would not feel rejected, where there would be no risk. A comfort zone. It’s the environment that makes all the difference.”*

*“The risk would be for my condition to be revealed without my consent. For me that is the number one hurdle. There continue to be many taboos associated with this disease...I am afraid of being judged. I am afraid of being poorly regarded. As if I was promiscuous. You need to be careful whom you tell.”*

*“...It is good to have a place where I can be myself...where there is no secrecy.”*

*“When it comes to HIV-related organizations, I am very open about being HIV positive. I have no problem with that.”*

## **Theme 5: Volunteering provides time structure**

For the participants, managing an infection like HIV requires time and flexibility. Indeed, some participants have to take several medications on a very regular basis and be under very strict medical care. Others have to deal with the uncertain course of the infection and the side effects of the medications. In other words, the participants find it hard to tell in advance whether their health will allow them to be active or if they will be forced to restrict their activities. Therefore, living with HIV means managing the unpredictable and living with uncertainty.

Despite the restrictions brought on by their HIV status, the participants are in fairly good health, allowing them to remain relatively active. If they have chosen to volunteer, it is precisely because of the flexibility inherent in this type of occupation. The flexibility enables them to reconcile the restrictions they are subject to because of their HIV status and to meet the requirements of their volunteering activities.

Therefore, volunteering allows the participants to structure their time realistically based on how they are feeling. This is an important factor in their decision to volunteer their services. Indeed, given that none of the participants have a gainful occupation, they have the time to volunteer. However, they do not want to suffer the disadvantages of the labour market without at the same time benefiting from the advantages it has to offer.

In other words, volunteering is an attractive option for the participants since their presence is not an absolute necessity, as it would be in a job. Under these conditions, caring for their health can remain their priority. Volunteering can be integrated into and adapted to the dynamics of their life as people living with HIV.

*“It’s part of my daily life.”*

*“Volunteering replaces work, but is more flexible.”*

*“It’s not always easy to make choices...but I have to have respect for myself because if I go too far it could be harmful to me...Sometimes, I have to say no to certain obligations and state my limits.”*

*“An organization once asked me to be an administrator. At the time I wasn’t feeling well, the indicators were not good. I would have liked to become involved, but I had to say no. I felt that my limits were respected.”*

*“It is not the center of my life. What comes first for me is taking care of myself...followed by my volunteering activities, which I can suspend at any time.”*

*“Sometimes, it’s hard to reconcile the two, my health and volunteering. But I have to be realistic and accept my limitations. It could be risky to do too much. That’s the beauty of volunteering, being able to let go if necessary.”*

## **Theme 6: Volunteering is a form of self-expression**

For the participants, living with HIV takes up a lot of space in their lives. This type of chronic disease requires constant and close management, in terms of time as much as in the cognitive and emotional resources it exhausts. Their HIV status is deeply embedded in their day-to-day life and is hard to escape.

How do you live with and in spite of this disease that cannot be ignored? It leaves little or no space for the participants themselves. They need a place to talk, to express and fulfill themselves, despite their infection. A place where the disease is no longer the central focus around which everything revolves, a place outside of its gravitational force.

For the participants, volunteering is, to a certain extent, that place partially out of the reach of the infection, a place where they can express themselves, talk and fulfill themselves, an escape from the reality of their infection. This aspect of their volunteering is very important for them. It is important because they can assert that their being extends beyond the boundaries set by the disease, boundaries often composed of discrimination, stigmas, concern, fear, loneliness, and suffering.

Volunteering is therefore a place where the individual can have the freedom to express his or her values, abilities, professional experience, in fact all of the knowledge, know-how and self-management skills patiently acquired throughout his or her life. Some participants even perceive volunteering as an extension of their professional career. It is a way for them to use their professional expertise for the benefit of others.

*“As an individual, it keeps me in contact with my profession...it’s a bit like an extension of my gainful occupation.”*

*“It’s become more important since I left the workplace.”*

*“It gives me an opportunity to accomplish things. It keeps me mentally active, it challenges my ideas, it is also fulfilling...”*

*“...It’s a creative activity. It allows me to express myself.”*

*“...I want to have the option of doing things I like, things that contribute to my personal growth and where I can learn to be creative.”*

### **Summary**

What have we learned after this first section focusing on the analysis of the participants’ testimonies? We now know that volunteering represents an important experience in the life of the participants in more than one regard. In fact, the benefits derived from the experience of volunteering are at once psychological, social, and vocational.

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## 4.2 Themes identified based on testimonies of managers of nonprofit organizations

### ***Theme 1: Value and general principle of inclusion of volunteers***

All of the organizations surveyed have a general outreach policy for welcoming individuals who want to volunteer. This policy can vary in form and content. Some organizations have developed explicit policies while others have implicit policies that only apply to the hiring of volunteers.

Whether implicit or explicit, tacit or written, such outreach policies reflect the principles of the Canadian Charter of Rights and Freedoms and the Ontario Human Rights Code.<sup>1</sup> The organizations surveyed all said that they reject any form of discrimination that could exclude volunteers for reasons of sexual orientation, of race or religious belief.

In other words, the organizations surveyed demonstrated a genuine concern for complying strictly with the spirit of the codes and charter. However, if some organizations show their endorsement of these values respecting diversity in an explicit and written manner, others do so in a more implicit and oral form. Therefore, as far as principles are concerned, the nonprofit organizations that took part in the research show a spirit of openness and acceptance.

*“We have a program for integrating volunteers. We ask people to sign a contract to commit their services for a minimum of six months. We also give them our code of conduct. Volunteers have to respect one another. Failure to respect...rights and freedoms while on duty is prohibited. If there is a complaint, management needs to see to it.”*

*“We have very strong tolerance values. Our organization is quite diversified. I believe a person living with HIV would feel quite welcomed.”*

*“There are no formal policies. But if a person living with HIV comes to us, we will make sure that he or she will be accepted by the group. We proceed on a case-by-case basis. The centre’s policy is: we’re the public service and therefore open to everybody.”*

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<sup>1</sup> See the Ontario Human Rights Code, which can be found on the Ontario Human Rights Commission website: <http://www.ohrc.on.ca> and the Canadian Charter of Rights and Freedoms which can be found on the Ministry of Justice website <http://www.laws.justice.gc.ca>.

## **Theme 2: Volunteering and the stigma of HIV/AIDS: A delicate balance**

In principle, nonprofit organizations ascribe to the tolerance and integration values advocated by the provincial codes and the Canadian Charter of Rights and Freedoms. In practice, these organizations operate in a social context that widely continues to attach a stigma to people living with HIV/AIDS. We note that these organizations are acutely aware of how widespread this taboo is within the general population and among their clients in particular.

### **Summary**

The review of the testimonies of the nonprofit organizations surveyed reveals that they too are affected by the same social stigmas as people living with HIV. Is this surprising? The answer is no. These organizations must learn to deal with reality as it exists around them. Their clients, just like their volunteers, might also harbour prejudices toward people living with HIV/AIDS. These organizations are in some ways caught between a “rock and a hard place.” By welcoming people living with HIV and fighting the stigmas that plague them, the organizations simply run the risk of alienating some of their clients and of losing some of their volunteers in the process.

*“When we use the words HIV/AIDS, people stop coming or come less often. To get people to come we have to use an indirect approach. If we recruit HIV-infected volunteers, we may not attract many people; they may be scared, and this is especially true among people who belong to groups where many stigmas are still attached to the disease...The taboo is still very strong... Prejudice is still very strong among our clients.”*

*“A campaign to recruit people living with HIV? Clients would have a negative reaction...People still don’t want to talk much about HIV, no one talks about it voluntarily.”*

*“The answer is no. Volunteer positions are open to everyone. We do not target specific people or groups. We are open to the overall population. The only criterion is to be Francophone...We have inclusion and anti-discrimination policies. Volunteers are made aware of the need for tolerance, but not specifically of HIV-related issues.”*

*“We are not looking to recruit infected individuals specifically. Recruiting is done through an announcement made to the general public, in newspapers, for example. But our campaign does not specifically target infected people.”*

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## 5. Conclusions and recommendations

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As our research covers both the volunteering experience of people living with HIV/AIDS and how well they are accepted in certain nonprofit organizations, this final section is divided into two parts. First, it deals with what this research reveals about the volunteering experience in an HIV/AIDS context and the resulting recommendations. Secondly, we proceed in a similar fashion with respect to the nonprofit organizations.

### 5.1 People living with HIV/AIDS and volunteering

It is clear that volunteering can hold a very important place in the life of certain people living with HIV. By volunteering, they can effectively re-energize several aspects of their lives. On a psychological level, they find a new meaning to their lives and give their self-esteem a boost. Socially, the participants can once again find their rightful place within their community and expand their social network. Finally, volunteering is viewed as an extension of their career enabling them to express themselves as individuals and to feel useful once again.

However, this volunteering occurs almost exclusively in organizations that specialize in providing services to people living with HIV/AIDS. The participants therefore avoid volunteering in organizations whose clients do not necessarily live with HIV/AIDS. This shows that they wish to avoid any type of discrimination, rejection or stigmatization, which is one of the participants' fundamental concerns. They only feel safe within organizations that deal with their condition.

This attitude on the part of the participants seems justified because the social stigma attached to HIV/AIDS remains exceedingly strong. These people are driven by some sort of protective instinct that makes them want to be in familiar territory and not venture off the beaten track.

### **Recommendations**

Considering how important volunteering is for certain individuals affected with HIV and the clearly positive effects of volunteering, our first recommendation is directed specifically to these people. We strongly believe that some of them should promote among their peers the inherent virtues of volunteering and what it has brought to their own lives. Often, first-hand testimonies are the best advertising. If people living with HIV/AIDS would speak up, this would make the best argument in favour of volunteering, one that would motivate their peers who have not yet become involved.

<b>Recommendation 1:</b>
It is recommended that people living with HIV/AIDS be invited to share their volunteering experience with their peers who have not yet volunteered so as to create an awareness about the positive effects of volunteering.

We believe this first recommendation could be implemented by voluntary and nonprofit organizations that take in HIV-positive individuals. For example, these organizations could partner with HIV clinics or community health centres so as to reach their clients who live with HIV/AIDS. An awareness campaign could also be launched targeting professionals working with affected people.



While it is important that people living with HIV/AIDS be the first to be made aware of the positive impact of volunteering, it is crucial for the general public also to be made aware. In fact, governments or certain organizations whose responsibility is to promote volunteering in general should publicize how volunteering can transform the life of an affected person and also how people suffering from HIV/AIDS could regain some of their dignity through participating in volunteering activities. This campaign would be beneficial to the volunteer community as a whole, but it would certainly have a positive impact on people living with a major chronic illness.

#### **Recommendation 2:**

It is recommended that public bodies and governments publicize the fact that volunteering can change the life of those who commit to it, so as to motivate people to do volunteer work and to prove that people living with a major chronic disease can still contribute meaningfully to their community.

## **5.2 Nonprofit organizations**

The review of the testimonies obtained from representatives of certain nonprofit organizations seems to confirm the concerns of the participants. As previously mentioned, these organizations claim to be open to all and to comply with the spirit of the charter that condemn discrimination of any kind. However, these good intentions cannot hide the fact that the organizations we surveyed still have to cope with the reality of the social stigma faced by people living with HIV/AIDS.

In other words, these organizations are not actively committed to the fight against stigmatization and the development of a policy to include people living with HIV/AIDS. The result of their passivity is to turn people away because to them these organizations are not places where they could be themselves without being judged and condemned.

Are the silence and passivity of nonprofit organizations questionable from an ethical perspective? We are tempted to say yes. In fact, this type of inactivity feeds irrational fears and false beliefs which can lead to the social stigma attached to people living with HIV. Ethically, the attitude of the organizations surveyed is also questionable as they do not sufficiently promote fairness and equality among all citizens.

Therefore, the results of our research are an invitation to voluntary and nonprofit organizations to show some ethical courage with respect to the issues surrounding HIV/AIDS. Of course, ethical judgement entails an often long and arduous thought process. There are no easy answers to any of these issues. We often have to tread in grey areas because of a need to find a balance between conflicting interests and competing values.

Regardless of these hurdles, voluntary and nonprofit organizations should, at the very least, start thinking about their policy for the inclusion of people living with HIV. One of the first questions would be simply to ask whether the organization has considered the specific nature of the HIV/AIDS issue as a whole, i.e. the terrible stigma to which are subject infected individuals who live with the virus. In other words, it is not enough for the organization to comply with the charter of human rights and freedoms. That is not enough. It may fulfill the legal obligation, but certainly not the ethical duty.

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## **Recommendations**

Voluntary and nonprofit organizations should therefore take a stand against the stigmatization of people living with HIV/AIDS. This is a first way to fight against such stigmatization since one of the characteristics of exclusion is the silence that surrounds it. Naming a taboo is already one way of demystifying it.

### **Recommendation 1:**

It is recommended that voluntary and nonprofit organizations have an explicit policy to include people living with HIV/AIDS and to fight against the social stigmas attached to this type of infection.

### **Recommendation 2:**

It is recommended that nonprofit organizations organize educational and information workshops for their clients and their volunteers so as to create an awareness of the life conditions of people living with HIV and to inform them objectively of the manner in which HIV is transmitted. These workshops could be facilitated in part by people living with HIV.

Finally, nonprofit organizations should try to reach out to people living with HIV/AIDS, in order to better understand their reality and their specific needs. This approach would build bridges and create links. Organizations would then be in a better position to set out policies for better integrating these people.

### **Recommendation 3:**

It is recommended that nonprofit organizations develop links with organizations working specifically with people living with HIV/AIDS. This is in order to create collaborative links for the well-being of their respective clients.



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