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Self-fulfillment despite barriers: volunteer work of people living with HIV

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With the decline in the morbidity and mortality associated with HIV infection, the majority of people living with HIV (PWHIV) experience a higher quality of life and longer life expectancy. Since this diagnosis no longer prevents an active lifestyle, many PWHIV are re-integrating into the workplace or are contemplating this possibility. Despite the multiple advantages associated with a return to work, research has identified barriers related to work and HIV infection. These barriers could prevent an important minority of PWHIV who wish to return to work from re-integrating into this environment. In this context, volunteering could be an alternate way to regain an active lifestyle. This research found that volunteer work allowed participants to enrich their social lives, to regain a sense of psychological well-being, and to apply their abilities to the benefit of others. However, participants are restricted by their preference to volunteer for HIV-related organizations in order to avoid social stigma and rejection.

Keywords: volunteer work; workplace barriers; vocational rehabilitation; job market re-entry; HIV/AIDS

Introduction

The aim of this qualitative study is to understand the experience of volunteer work of people living with HIV (PWHIV). Specifically, we attempt to answer the following questions: what does volunteer work bring to these individuals? How does volunteer work differ from remunerated work? What are the advantages and disadvantages related to volunteer work? The context of this research stems from the late 1990s, when the prognosis associated with HIV infection changed markedly. The advancement of scientific knowledge and new pharmacological therapies have led to the suppression of HIV replication in infected individuals and the concomitant recovery of immune function. This in turn has led to a dramatic decline in the morbidity and mortality associated with HIV infection (Werth, Borges, McNally, Maguire, & Britton, 2008). As a consequence, the majority of PWHIV experience a higher quality of life and longer life expectancy, a recent study from Denmark estimated the median survival time for a young person diagnosed with HIV today at 38.9 years (Lohse et al., 2007).

In view of the fact that AIDS is now a chronic illness, living with the infection does not prevent the possibility of working. A study conducted in the USA involving 200 participants living with HIV found that 40% of subjects were working and that 66% of those who were not employed were actively seeking re-entry

into the job market (Blalock, McDaniel, & Farber, 2002). Another American study reflects similar findings, where among 757 PWHIV who were not working, 74% were actively looking for a job (Brooks, Martin, Ortiz, & Venigas, 2004).

Literature review

Many factors can motivate a return to the job market. A qualitative study identified some of these motivations and showed that for the 30 participants, working helped them to feel useful and fulfilled as individuals (Brooks & Klosinski, 1999). Work also restores meaning to people's existence, gives them the opportunity to contribute to society, to expand their social network, and to regain a sense of normality. In addition, remunerated work leads to certain financial independence and could alleviate social shame and stigma associated with being on social assistance (Conyers, 2004).

In a study by Blalock et al. (2002), participants living with HIV who were employed reported significantly higher perceived quality of life than did unemployed participants. This finding supports the increasingly evidence-based idea that work is a contributing factor to recovery and healing (Escovitz & Donegan, 2005). People who successfully return to work after a period of disability have better health indices and shorter durations of disability than people

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who do not return to work (Martin, Steckart, & Arns, 2006).

Although research has shown evidence of certain undeniable benefits related to returning to work, job market re-entry for PWHIV is a complex process and, in certain circumstances, may require professional assistance (Escovitz & Donegan, 2005). For some authors, living with HIV constitutes a handicap and returning to work requires a similar form of assistance generally provided to those with a physical disability (Arns, Martin, & Chernooof, 2004).

Research has identified many types of obstacles, which can be medical, professional, social, or financial in nature (Goldblum & Kohlenberg, 2005; Martin, Brooks, Ortiz, & Venigas, 2003; Martin et al., 2006; Werth et al., 2008). A 2006 study found that 91.3% of 235 HIV-positive participants had experienced at least one kind of barrier during their efforts to return to work (Martin et al., 2006).

First, obstacles of a medical nature are directly related to the consequences of the infection. It remains difficult to predict the rate at which immunodeficiency will develop due to HIV infection and exactly when anti-HIV therapy will be required (Argentier, Fernet, Levy, Bastien, & Fernet, 2003). This uncertainty in prognosis and difficulties anticipating medical intervention can weigh heavily on individuals and their expectations of the future. While recent experience would suggest that most PWHIV could anticipate ongoing good health, many issues, such as the development of drug-resistant virus, remain undefined. Professional development and its planning carry the weight of this incertitude (Brooks & Klosinski, 1999; Hoffman, 1997; Martin et al., 2003). One of the more significant side effects associated with HIV treatment is lipodystrophy or body fat redistribution. Individuals with lipodystrophy lose fat from their face, arms, legs, and buttocks and gain fat in the abdomen and upper back. For some, this fat redistribution can be significant and disfiguring. This not only can affect self-esteem, but can also significantly impact those whose occupation involves interaction with the public (Argentier et al., 2003). In addition, there is fear that stress related to work could be detrimental to overall health or that the workplace could constitute an environment, where there is a risk of contracting an infection (Arns et al., 2004).

In summary, a realistic return to the job market must take into consideration the individual's health status. The professional occupation must be adjusted to the limits and boundaries associated with the illness (Hunt, Jaques, Niles, & Wierzalis, 2003). For the poor or near poor, issues of finding a job and keeping it often take precedence over larger decision-

making processes, such as choosing among a variety of job opportunities (Werth et al., 2008).

The second type of barrier is associated with career issues and its development. Not only PWHIV are confronted by the general situation of a competitive job market and the requirement of holding a sufficient level of employability, but also, they must live with an infection that inherently limits their employment opportunities. For example, PWHIV require ongoing medical care and monitoring. This level of care, usually provided by specialists, is generally accessible only in larger urban centers. Such restriction in job mobility can affect opportunities for advancement and promotion (Timmons & Fesko, 2004).

A qualitative study by Maguire, McNally, Britton, Werth, and Borges (2008) showed that PWHIV could be forced to find new types of employment, as their current or past professional activities had become too physically demanding and their bodies could no longer tolerate the stress. Furthermore, an employment barrier exists for those who lack job-related skills other than the physical or labor-intensive ones for which they have been originally trained.

The third type of obstacle is associated with social stigma. Social stigma continues to negatively affect the lives of PWHIV (Herek, Capitanio, & Widaman, 2002). This phenomenon can greatly counter efforts for re-entry into the job market. The majority of PWHIV experience some form of rejection in the workplace (Brooks et al., 2004). Specifically, they worry that the accidental disclosure of their condition may lead to a form of exclusion, slow the progression of their career, or even lead to their job termination (Brooks & Klosinski, 1999; Hoffman, 1997). A recent study confirms that PWHIV still not only experience stigma, but also different forms of abuse (Maguire et al., 2008).

Social stigma may also manifest itself in an insidious manner. For example, PWHIV worry about feeling uneasy while explaining or justifying their need to take medications or having doctors' visits during work hours (Hunt et al., 2003). There is also the concern about the possible feeling of humiliation that could be associated with the bureaucratic procedures necessary to obtain benefits (Conyers, 2004).

The fourth type of barrier is financial in nature. The return to work usually leads to the cessation of long-term disability benefits. This possibility can cause worry to the point of indefinitely postponing any form of vocational rehabilitation (Brooks et al., 2004; Ferrier & Lavis, 2003). A 2004 study found that 73% of a 536 sample of currently unemployed PWHIV, who were contemplating return to work,

ranked “fear of losing disability income benefits” on a survey as the most significant barrier to return to work (Brooks et al., 2004).

In conclusion, many obstacles confront PWHIV who wish to return to work and further their career. Even if work seems to be a realistic possibility for a number of PWHIV, returning to the workplace could be out of reach for some. In these circumstances, volunteer work may constitute a more realistic option. Research has shown that volunteer work in other medical and social contexts could be a form of personal investment and achievement. According to our own investigation, almost no research has examined volunteer work and PWHIV (Conyers, 2004).

Methods

The Empirical Phenomenological Psychological (EPP) data analysis method proposed by Karlsson (1993) was used in this study. This method is divided into five stages, which were followed in the present research. The first in the process is to carefully read and reread each individual participant’s testimony in order to reach an empathetic understanding of the subject’s experience. In the second stage, each verbatim is separated into individual units of meaning. During the third stage, the units of meaning of each verbatim are interpreted and an initial abstraction of the meaning is made. In the fourth, each verbatim is interpreted to the highest level of abstraction possible in order to draw out the essential elements of the experience as perceived by the participant. Finally, in the fifth stage, the common elements of testimony are identified and the essential elements are described.

This research was publicized through AIDS community-based organizations dedicated to serving persons living with HIV/AIDS. One organization was situated in the area of the National Capital of Canada (Ottawa-Gatineau) and the other organization was situated in the Greater Toronto area, also in Canada. To be eligible, the participants were required to live with HIV for a period of at least five years prior to the study’s interview. The research was conducted in French and all 12 participants were of French Canadian descent and volunteer workers living in the area of either Ottawa-Gatineau or Toronto. Participation to this study was open to men and women, whether they were heterosexual, gay, lesbian, bisexual, or transgendered. However, all participants who responded to the survey were men who have sex with men (MSM).

Semi-structured interviews were conducted in French, were taped, and later transcribed. The

average length of the interviews was 90 minutes. Each participant was asked to describe his experience of volunteer work, using a written Question Guide (see Appendix 1).

Results

Upon our phenomenological analysis of participant interviews, three major themes were identified. These themes are: the social dimensions of volunteering, the psychological dimensions of volunteering, and the vocational dimensions of volunteering. In other words, volunteer work is experienced in relation with others, influences one’s self-perception, and renews one’s career path.

Theme 1: Volunteering and social life

All the participants found it hard to live with the social stigma that was and continues to be attached to HIV. They feel judged and rejected. Most of them hide their condition and only tell their loved ones or to 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 PWHIV, 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 bridges, creating links, or just simply enjoying the company of others. In addition, most participants say that they prefer to work for non-profit organizations providing services to PWHIV and who are gay. 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 have 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. Not only does it help to put an end to isolation, but also the participants often discover a true community life where they can grow (see Appendix 2).

Theme 2: Volunteering and psychological well being

According to the participants' testimonies, volunteering helps them to enhance their self-image. Volunteer work within AIDS service organizations provides a place, where a person can develop a self-image that is unaffected by the negative influence of surrounding prejudices. It provides an environment free of any social stigma, where the affected person can rebuild a more positive self-image. In other words, volunteering within these organizations provides a shelter, where participants can be themselves without fear of being rejected because of their HIV status. This allows the individual to express himself, to become committed, and to grow on a human level by doing something useful. Participants regain their self-confidence, rediscover their ability to be friendly, and learn that others do care.

Volunteering also helps the participants to enhance their self-image through commitment to new challenges, and through rediscovering pre-existing and developing new personal skills. They are finally able to perceive themselves in a new light; instead of receiving care and feeling dependent, they develop a sense of usefulness and reciprocity. Simply put, they feel better (see Appendix 2).

Theme 3: Volunteering and vocational implications

For the participants, managing their HIV infection requires time and flexibility. Indeed, those participants on HIV therapy are required to take their medications on a very regular basis and remain under close medical supervision. Others have to deal with the uncertain course of the infection and with not knowing exactly when medications will be required. 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. 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 infection while meeting the requirements of their volunteering activities.

Therefore, volunteering allows the participants to structure their time realistically. 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. 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 paid 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 PWHIV.

For the participants, volunteering is, to a certain extent, a place where they can express themselves. This aspect of their volunteering is very important for them because they can assert that their being extends beyond the boundaries set by the infection. Volunteering is therefore a place where the individual can have the freedom to express his values, abilities, professional experience, knowledge, know-how, and self-management skills, patiently acquired throughout his 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.

For the participants 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 volunteer work. In a way, volunteering becomes a center of gravity that organizes their life and gives it some direction. Participants regain a sense of usefulness because they can contribute to society and become actively involved.

Discussion

One of the more interesting conclusions of this qualitative research is that participants justify their choice to volunteer for HIV/AIDS organizations by explaining that they wish to avoid discrimination and social stigma. In other words, when it comes to volunteer work, PWHIV choose to contribute within organizations that deal with their condition. By doing so, they avoid any form of stress associated with social stigma. The participants are driven by some sort of protective instinct that makes them want to be in familiar territory rather than to venture off the beaten track, and to be in an environment where HIV is not considered unusual. Volunteering within an HIV/AIDS organization can provide a unique sense of belonging.

In comparison to paid work, where secrecy seems to be the solution used to avoid the social stigma associated with HIV infection, when it comes to volunteer work, the choice of the right organization seems to be the solution to prevent the same kind of social alienation. Both cases illustrate protective

measures, the first leads to clandestinity and the second limits one's choices.

Nevertheless, volunteering helps participants to expand their social network in a secure context. It is even for them a way to find social support. Indeed, our phenomenological analysis indicates that participants experience a very rich community life, where they sometimes create close social relationships, and are able to share their own experiences openly and freely. This very special quality of their social network is different from what is usually experienced in a workplace context. According to research, the workplace constitutes one of the main sources of social stigma for those with HIV infection (Brooks et al., 2004), where PWHIV live under the constant threat of accidental disclosure (Maguire et al., 2008). In contrast, volunteering in organizations dedicated to HIV/AIDS seems to relieve participants of this particular fear and anxiety.

From a psychological point of view, our phenomenological analysis shows that volunteering promotes well-being. First, volunteering helps PWHIV to develop a more positive self-image and gain a new sense of self-worth. Participants feel more useful and self-confident. In other words, the experience of volunteerism provides new meaning and new direction to participants' lives. These advantages provided by volunteer work could be compared to those provided by a paid job. As previous research shows, work restores meaning to existence, gives a new sense of normality (Brooks & Klosinski, 1999; Conyers, 2004) and promotes, as volunteering does, an overall sense of well-being (Blalock et al., 2002). In addition, according to our research, it seems that volunteering could be less stressful than work because individuals are less likely to encounter social stigma.

From a vocational point of view, volunteering seems to provide one major advantage compared to work: flexibility. Participants can decide not to show up for their volunteer work if they feel they are not physically well enough. Indeed, research shows that it is sometimes difficult to maintain a paid job and, at the same time, live with the medical limitations imposed by HIV (Brooks & Klosinski, 1999; Hoffman, 1997). Finally, our research participants do not have to face the demands that come with today's workplace challenges: competitiveness, maintaining and developing new skills, and work-related transitions (Maguire et al., 2008; Timmons & Fesko, 2004). On the other hand, participants do not benefit from financial autonomy usually associated with a paid job.

In summary, volunteer work provides flexibility, freedom, and at the same time, some of the advantages usually associated with work. In fact, when it

comes to social networks, those advantages seem even greater. By working for HIV/AIDS organizations, participants avoid social stigma and they are able to live with their infection openly. However, it must be recognized that they are still living in a marginalized segment of society. Overall, volunteer work is free of many disadvantages and at the same time provides many of the advantages related to remunerated work.

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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 toward 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?

Appendix 1: Question guide

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?

Appendix 2

<i>Theme 1: Volunteering and social life</i>	<i>Volunteering and psychological well being</i>	<i>Theme 3: Volunteering and vocational implications</i>
<p><i>“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.”</i></p>	<p><i>“It lets me play a role in my community, otherwise I would be totally dependent on others.”</i></p>	<p><i>“Volunteering replaces work, but is more flexible.”</i></p>
<p><i>“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.”</i></p>	<p><i>“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></p>	<p><i>“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.”</i></p>
<p><i>“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.”</i></p>	<p><i>“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.”</i></p>	<p><i>“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.”</i></p>
<p><i>“When it comes to HIV-related organizations, I am very open about being HIV positive. I have no problem with that.”</i></p>	<p><i>“It’s a way to achieve self-fulfillment . . .”</i></p> <p><i>“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 . . .”</i></p>	<p><i>“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.”</i></p>
	<p><i>“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.”</i></p> <p><i>“As an individual, it keeps me in contact with my profession . . . it’s a bit like an extension of my gainful occupation.”</i></p>	