

Ageing with HIV/AIDS: a scoping study among people aged 50 and over living in Quebec

ISABELLE WALLACH* and SHARI BROTMAN†

ABSTRACT

The population of people aged 50 and over represents a significant proportion of people living with HIV in Western nations. While the number of older people living with HIV is rapidly increasing in Canada, research originating in this country remains relatively scarce. This article therefore proposes to describe the impact of the intersection of HIV and ageing on the identities and lived experiences of people living with HIV of 50 and over (PLHIV₅₀₊), both on an individual and social level, in order to offer a picture of their lived experience. Using a phenomenological approach, nine semi-structured individual interviews with PLHIV₅₀₊ (men and women) were undertaken. Data analysis identified several central themes which constituted the essence of their experience of the intersection of HIV and ageing, such as the experience of premature ageing, the impact of HIV on intergenerational relationships, the shrinking of one's social network, rejection experienced by the older population, a difficult return to work and a deterioration in living conditions. The results of this research highlight the many challenges faced by PLHIV₅₀₊, on physical, relational, work and economic levels. Even though some of the problems faced by PLHIV₅₀₊ were related to the experience of corporal changes and a deterioration of health, our research was able to highlight the societal and structural factors underlying the stigma of HIV and ageing.

KEY WORDS – HIV/AIDS, premature ageing, body, stigmatisation, social inclusion, economic situation.

Introduction

The population of persons aged 50+¹ has experienced a steady rise in the rate of Human Immunodeficiency Virus (HIV) since the early 1990s. Today, the 50+ population represents a significant proportion of those with HIV in Western nations. This phenomenon is primarily explained by the transformation of the HIV infection into a chronic illness and the

* Département de sexologie, Université du Québec à Montréal, Montréal, Canada.

† School of Social Work, McGill University, Montréal, Canada.

introduction of Highly Active Antiretroviral Therapy (HAART) in 1996, which allowed for a considerable increase in life expectancy for people living with HIV (PLHIV). Moreover, there has been a significant increase of those newly diagnosed with HIV among people 50 years of age and older. In Canada, in 2008, for example, 21.6 per cent of Acquired Immune Deficiency Syndrome (AIDS) cases and 15.3 per cent of those newly diagnosed with HIV, were made up of people 50 years of age and older (Public Health Agency of Canada 2010). Despite the steady increase in the number of ageing people living with HIV in North America and Europe, few efforts have been made to target older people for prevention or health promotion programmes (Altschuler, Katz and Tynan 2004; Coon, Lipman and Ory 2003; Fritsch 2005; Lebouché, Wallach and Lévy 2008).

The situation may also be problematic in developing countries. Several authors have identified the deplorable lack of epidemiological data that could support the development of more accurate estimates of the prevalence and incidence of HIV among individuals aged 50 and over in those countries (Mutevedzi and Newell 2011; Schmid *et al.* 2009; Wilson and Adamchak 2001). According to Knodel, Watkins and VanLandingham (2003), statistics collected by national programmes and reported to the World Health Organization (WHO) in 1999 demonstrated that the rate of AIDS cases among people aged 50 and over were lower in Asia, Africa and Latin American than in economically more developed countries. Thus, people aged 50 and over represented 5.6 per cent of all AIDS cases in Africa, 4.5 per cent in Asia and 7.4 per cent in Latin America. The authors accounted for these low percentages by highlighting the realities that there are generally lower proportions of seniors in the developing world, and that poor access to efficient HIV treatments reduces the life expectancy of PLHIV in those countries.

However, more recent works provide alarming data about older adults living with HIV in the developing world. A report attempting to quantify the prevalence of HIV infection among older adults in sub-Saharan Africa estimated that people living with HIV of 50 and over (PLHIV₅₀₊) represent 4 per cent of the general population 50+ in this part of the world and 14.3 per cent of PLHIV over 15 years of age (Negin and Cumming 2010). In South Africa, a national study reported an HIV prevalence of about 10 per cent among adults between 50 and 54 years of age (Mutevedzi and Newell 2011). No recent data are available on the prevalence of HIV among people aged 50 and over in Asia, as reports only document HIV rates among 15–49-year-olds (WHO 2010). The lack of data available about PLHIV₅₀₊ living in developing countries may also be explained by taboos and ageist stereotypes surrounding senior sexuality in those countries (Negin and

Cumming 2010; Sankar *et al.* 1998), thereby limiting research on HIV issues among this age group.

The invisibility of older people with HIV/AIDS in prevention, health promotion and treatment programmes exacerbates this growing problem, in Western countries (Lebouché, Wallach and Lévy 2008; Wallach 2008) as well as in developing countries (Knodel, Watkins and VanLandingham 2003; UNAIDS 2009; Wilson and Adamchak 2001).

Several studies have been conducted in the United States of America (USA) and the United Kingdom on the various issues that may be confronted by people 50 years of age and older living with HIV (PLHIV₅₀₊) (Brennan *et al.* 2009; Karpiak, Shippy and Cantor 2006; Power, Bell and Freemantle 2010). Research on the situations and experiences of PLHIV₅₀₊ in developing countries is, however, almost non-existent. Most studies have focused solely on older adults *affected by HIV/AIDS* 'who, even though not infected themselves, may be affected by the illness and death of others who are' (Williams, Knodel and Lam 2010: 3). According to studies realised in developed countries, older people living with HIV experience a multitude of challenges in their lives. Research results highlight the fact that, on a psychological level, people often experience a deterioration of their self-image, feel shame or guilt with respect to their HIV diagnosis, and fear rejection or discrimination by others (Emlet 1997, 2007; Nichols *et al.* 2002). According to Emlet (2008), these feelings may be a manifestation of an internalisation of the stigma.

Several research studies realised in developing countries have focused on the social challenges of living with HIV, addressing relational, professional and socio-economic realities. With respect to social relationships, studies have highlighted the fact that PLHIV₅₀₊ experience stigma related to HIV status and/or ageism (Emlet 2006a, 2007; Karpiak and Shippy 2006; Power, Bell and Freemantle 2010). This stigma includes experiencing negative reactions from others (including family, colleagues, friends, *etc.*), facing fear of contagion and rejection. Isolation and loneliness were also identified as major issues in the experience of PLHIV₅₀₊ (Brennan and Applebaum 2009; Crystal *et al.* 2003; Emlet 2006c; Power, Bell and Freemantle 2010).

While there are almost no data concerning PLHIV₅₀₊ in developing countries, a study conducted in Asia suggested that HIV stigma might be amplified for older adults with HIV, as a result of negative prejudices regarding senior sexuality. Based upon an analysis of attitudes toward HIV and toward sexuality of elderly people in Thailand and India, Sankar *et al.* (1998) identified that older adults living with HIV are at high risk of being stigmatised, due to cultural norms that assume withdrawal of elderly people from sexual activity.

Older PLHIV maintain few relationships with their biological family and generally receive little support from them. The support that PLHIV₅₀₊ receive comes primarily from their friendship networks developed since their diagnosis (Karpiak and Shippy 2006; Shippy and Karpiak 2005). Given the reality that friendship networks are often made up of those also living with HIV, the social networks of this cohort can be experienced as fragile (Poindexter and Shippy 2008).

The socio-economic situation of PLHIV₅₀₊ is often characterised by unemployment, often linked to HIV status. PLHIV₅₀₊ experience health consequences that make it difficult to find or retain full-time employment (Power, Bell and Freemantle 2010; Karpiak and Shippy 2006; Nichols *et al.* 2002). This situation results in significant financial insecurity and vulnerability to material difficulties. Nevertheless, it is important to underline, that according to studies conducted in the USA, this economic insecurity is directly linked to individuals' socio-economic status prior to infection (Crystal *et al.* 2003; Joyce *et al.* 2005). This research suggests that older ethnic minority men, who experience high rates of poverty and unemployment, are confronted with significantly more economic difficulties when diagnosed with HIV when compared to all older Caucasian men who have sex with men (MSM). This is exacerbated by precarious medical insurance status among these populations.

In the context of developing countries, the magnitude of the HIV pandemic has been reported as significantly compromising the economic security of PLHIV₅₀₊. Many studies raise the issue of the economic burden on African grandparents, and especially on grandmothers, who have had to provide care and financial support to their children suffering or dying of HIV/AIDS, and to their orphaned grandchildren (Hosegood and Timaeus 2006; WHO 2002; Wilson and Adamchak 2001). Caring for HIV-infected family members by people from older generations is a topic also mentioned in studies carried out in South-East Asia (Knodel 2008; Knodel *et al.* 2001). It may be assumed that older adults who are themselves infected by HIV are further impoverished by this financial responsibility, even though no empirical research has yet been conducted on this question (IDASA 2011).

Although the research on HIV and ageing provides an overview of the experience of PLHIV₅₀₊, it is far from exhaustive. The scholarship in this area has only begun to emerge in the past decade, and research originating in Canada is relatively sparse. To date, studies in Canada have largely focused upon access to health and social services (Fritsch 2005; Furlotte 2009). These studies, however, do not address the lived experience of ageing and HIV. The intersection of ageing and HIV status as a significant marker of identity is an important area of inquiry. In order to fill this gap, our research aims to explore the experience of people in Quebec who live at

the intersection of HIV and ageing. Our objective is to highlight the critical issues confronted by PLHIV₅₀₊. This article proposes therefore to describe the impact of the intersection of HIV and ageing on the identities and lived experiences of PLHIV₅₀₊, both on a psychological (ageing experience, body image, self-perception) and social (relational, professional, socio-economic) level, in order to offer a picture of their lived experience. It is hoped that an exploration of the complex lived experience of this cohort of people under-represented in the current literature will help to illuminate the challenges facing this population and ultimately provide health and social service professionals with strategies for outreach to, and work with this invisible population of seniors.²

Theoretical framework

The current project was designed using an intersectionality³ approach in order to facilitate an examination of how individuals live their identities as PLHIV₅₀₊ in the context of broader structural forces of discrimination made manifest through social and institutional relationships. From this perspective, such issues as stigma, self-concept, social support and life satisfaction are not seen simply as individual experiences or methods of coping with illness, but rather are understood as social phenomena, mediated by and through complex relationships of power within society. As such, the lived experience of ageing in the context of HIV is conceptualised through the lens of interlocking systems of domination and oppression whereby people both act and are acted upon through institutional and social relationships marked by sexism, heterosexism, classism, ageism and other forms of discrimination. This is particularly salient for individuals living with HIV for whom stigma surrounding the illness has been well documented. Therefore, exposing these complex realities requires an exploration grounded in an examination of the ways in which individuals live various marginalised social locations *simultaneously*. To this end, our approach also draws from sociological and anthropological traditions that address questions of ageing and illness, notably through the articulation of three central concepts, namely biographical transitions, significance and embodiment.

The first concept which is central to our study is that of *biographical transitions and their consequences*. This concept has been explored extensively in sociology from the distinct perspectives of ‘ageing’ and ‘illness’ as separate spheres of study.

In the field of sociology of illness, the concept of *biographical disruption* has incorporated the experience of chronic disease since the early 1980s

(Bury 1982). According to Bury (1982), chronic disease is an event that disrupts the structures of daily life, knowledge and interpersonal relationships, affecting, in particular, taken-for-granted assumptions, behaviours and explanatory systems including the person's biography and self-concept. Although this theoretical framework has formed the basis of numerous works on the experience of chronic disease, it has also been the subject of much criticism, which has stressed the fact that the phenomenon of disruption associated with illness is far from systematic and requires contextualisation (Pound, Gompertz and Ebrahim 1998; Sanders, Donovan and Dieppe 2002; Williams 2000). Williams (2000: 55) nonetheless states that 'biographical disruption exists in the real lives and real worlds of sentient subjects and sociopolitical agents, however "mediated" this might be'. Even though illness is not necessarily experienced as disruptive (Carricaburu and Pierret 1995), research on the experience of living with HIV has widely underlined the many areas of life that could be affected by such a diagnosis (Lévy, Pierret and Trotter 2005; Mendès-Leite and Banens 2006; Pierret 2006). In order to acknowledge theoretical critique while at the same time retaining the central position of Bury's concept, we have chosen to integrate the term –borrowed from the field of gerontology– of *biographical transition* into our framework. This enables a focus upon an evolution in the biographical journey without conveying a connotation of sharp break. Our research objective, therefore, becomes one which is centred upon an exploration of the biographical changes induced by HIV through which ageing-related changes interact to produce unique effects and experiences.

According to the lifecourse perspective, individuals experience different transitions during their life paths that mark the beginning of new roles and new stages, such as the end of studies, marriage or retirement (Grenier and Ferrer 2010). Sociologist of ageing Caradec (2004, 2008) proposes to consider the multiple biographical changes that accompany ageing (retirement, widow(er)hood, moving into a seniors residence, approaching of death) as biographical transitions, effecting or transforming identity. According to Caradec (2008), these transitions generate three major repercussions, namely a redefining of identity, a transformation of relational environment and a deconstruction of daily life's 'taken-for-granted'. Caradec also considers that, in addition to these biographical changes, the deterioration of physical ability and vital energy has an impact on social life, by forcing people to give up certain activities and relationships, which he refers to as 'déprise'. On the basis of his work, we propose a consideration of ageing itself as a biographical transition, generated by the overall social and biological changes that occur during the period culturally defined as ageing, the impact of which is important to determine.

Although studies in sociology of illness underline the importance of taking age into consideration when analysing experience of chronic disease (Pound, Gompertz and Ebrahim 1998; Sanders, Donovan and Dieppe 2002), and although research in the sociology of ageing acknowledges the role of physical health deterioration in the life transformation process that characterises this stage of life, few theorists in the sociology of ageing and illness have yet integrated these multiple transitions into a theory which accounts for both ageing *and* illness. Our research will focus on the effects of biographical transitions on various spheres of individuals' lives, in order to identify the changes, limitations and difficulties they are confronted with because of biographical transitions due to HIV and ageing.

The second central concept on which our research is based is the signification associated with biological phenomena, whether it be physical ageing or illness. The aforementioned sociological studies analysing the experience of illness also stress the importance of considering the significations associated with it. Bury (1988), in his analysis of chronic disease, actually establishes a distinction between two types of meaning, meaning as consequence and meaning as significance. Whereas the first term designates the practical consequences and difficulties that the disease creates in individuals and their families' everyday life, 'meaning as significance' refers to the symbolic significances and connotations conveyed by chronic disease. In the same way, interpretive medical anthropology (meaning-centred) considers that illness is fundamentally semantic and varies according to individuals and groups. A symptom or a disease condenses the network of a sufferer's personal meanings⁴ which is itself taking root in the network of a society or subculture's significance of illness. According to Good and Delvecchio Good (1980: 177), 'The symptom can only be interpreted within a personal and social context. For the individual sufferer, personal meaning is joined with social signification to form a unique illness reality'.

In the same way, critical gerontology and sociology of ageing highlight the individual and social meanings associated with ageing. Representations of age advancement, their institutional categorisations, as well as the ageing experience, differ depending on individuals and social groups. According to critical gerontology, 'ageing and old age are socially constructed within educational, family, legal, welfare and healthcare institutions' (Katz and Marshall 2003: 3). Henceforth, critical gerontology underlines the blurriness of boundaries between the different stages of life, which affects the contemporary social perception of ageing (Featherstone and Hepworth 1991; Jones 2006; Katz and Marshall 2003). At the same time, the variation of individual meanings associated with ageing is demonstrated through the phenomenon of appropriating or distancing oneself from the category of

'elderly person' (Caradec 2004; Jones 2006), or from the classifications made around ageing (Grenier 2007). Critical gerontology thus highlights clearly the variability of ageing and age perception which is, according to Grenier and Ferrer (2010: 47) 'much more personal, subjective and fluid than the divisions based on chronological age'. The social construction of ageing and of HIV also manifests through the negative representations that are associated with them. Following the seminal work of Goffman (1968), many studies highlighted the existence of a stigma related to HIV (Herek and Capitano 1998) and a stigma related to age which manifests through the phenomenon of ageism (Butler 1969). Far from being just symbolic, these meanings have major consequences on the lives of individuals. Depending on the form it takes, stigma may have repercussions on self-image or may be at the origin of experiences of discrimination. The studies on stigmatisation revealed that stigma can take on two forms: 'felt', which makes reference to a feeling of shame or fear of experiencing discrimination, and 'enacted', which refers to real episodes of discrimination (Emlet 2006a; Scambler 1993). In the context of this research, we are interested in the meanings associated with ageing and HIV and, in particular, the impact of these negative meanings on the phenomenon of stigmatisation.

The third aspect that is important to consider in a research study on PLHIV₅₀₊ is the concept of embodiment. Given the combined experience associated with the undesirable effects from medications over the long term, HIV and the premature physical ageing to which they are susceptible, it seems essential to integrate a corporal dimension in the analysis of life experience. Inspired from phenomenology, some anthropologists believe that the body is of central importance and consider it to be the point of departure with respect to the experience of the individual and self-perception (Csordas 1994; Good 1998). According to Good (1998: 246), the body constitutes 'an essential part of oneself' for the person who is ill such that an anthropological study of illness cannot obscure the subjective corporal experience. Research in social gerontology has also focused on the body, underlining its involvement in the construction and negotiation of elderly people's identity (Biggs 1997; Featherstone and Wernick 1995) or analysing it as a place of resistance, whether it is related to the issue of appearance (Hurd Clarke 2002) or to the categorisation of the body depicted as in decline and/or frail (Grenier and Hanley 2007). Others have conceptualised the ageing body as a mask, external signs of ageing being perceived as contradicting the inner feelings of age and the still young identity hiding behind the outward appearance (Biggs 1997; Featherstone and Hepworth 1991). Heikkinen (2000: 474) states the bodily experience 'is the key issue in experiencing ageing' and proposes to put the discourse on body at the centre of the analysis of the ageing process. She notably asserts

the importance of articulating an analysis of bodily experiences, of their meanings in people's lives and of the ways in which they influence existence (Heikkinen 2000).

Within this perspective, this research will focus on the corporal experience of individuals in order to try to understand the way in which it shapes self-perception and the existence of PLHIV₅₀₊.

By incorporating the concepts of embodiment, social meanings and biographical transitions and their consequences as theorised within the framework of a socio-anthropological approach, we are able to position ourselves and our research within a tradition of inquiry embedded in explicating the meanings associated with the intersectional experience of ageing and HIV.

Methodology

We used an adapted phenomenological approach in order to understand the meaning older people attribute to their experience of living with HIV (Creswell 1998; Moustakas 1994; Tesch 1990). Phenomenology is a qualitative methodological approach designed to render explicit the essential meanings attributed to the lived experience of a particular phenomenon and engages with the subjective experience as a means of both data collection and analysis (Bogdan and Biklen 1982). A phenomenological approach focuses on understanding how people experience a situated phenomenon, such as is the case of living with HIV at 50 years of age and over, through conversation between researcher and research subject. Questions are broad and give room for the participant to tell the story of their experience. An emphasis in both data collection and analysis is placed upon how meaning is made of the lived experience. While phenomenological approaches tend towards unstructured interviewing techniques which engage the participant in an open dialogue in which analysis focuses both on the story itself and the meaning (developed through language and emphasis) attributed to that story, recent phenomenological accounts have also used semi-structured interviewing techniques to focus participants on particular aspects (themes) of a phenomenon (Beharry and Crozier 2008; Haj-Yahia and Cohen 2009; Wimpenny and Gass 2000). Moustakas affirms that the interview guide can 'facilitate the obtaining of rich, vital, substantive descriptions of the co-researcher's [participant] experience of the phenomenon' (1994: 116).

The principal selection criteria for participants in the current study were designed to locate individuals who experienced the phenomenon under study, which is living with HIV at 50 years of age or over. Date of diagnosis

ranged considerably within the sample with some diagnosed in their fifties and others diagnosed in their late thirties or forties. All participants were infected as a result of sexual contact. The sample was diversified in terms of gender, sexual orientation and age, in order to reflect some of the diversity of the population of PLHIV₅₀₊. Sample size in the current study was limited (nine individuals) as is consistent with a phenomenological approach. This is done as phenomenology focuses on in-depth conversations with individuals about their lived experience of the same phenomenon (that is living with HIV at 50+ years) in order to examine the essence of that experience for those individuals, rather than on representation or generalisation to the whole population. Despite the small sample size it was challenging to locate potential participants due to the invisibility of this population in a variety of sectors and communities.

Participants were recruited through three organisations serving people living with HIV. The first organisation served the population defined as men who have sex with men (MSM) which is made up primarily of gay and bisexual men. The second organisation targeted women and the third focused on housing issues for those with HIV (convalescence home, social housing). Given the general problem of the lack of services intended specifically for the senior population of PLHIV, these organisations attracted a restricted number of clients aged 50+, contributing to significant delays in recruitment. This was extended considerably to allow for prolonged engagement in the field in order to build linkages with key informants for the purposes of outreach and recruitment. Finally, as a result of conversations with key informants in the ageing sector who identified the almost absolute invisibility of PLHIV in these organisations and the stigma related to coming out in this sector, we decided not to recruit participants through senior-serving organisations.

In total, five men and four women aged 50 years or over and living with HIV were interviewed. These participants were aged between 50 and 68 years old. With respect to their sexual orientation, four respondents identified as gay and one man and four women identified as heterosexual. All of those recruited to participate in the study were francophone.

Following phenomenological methodological principles developed by Moustakas (1994), our study includes several semi-structured theme areas in order to both allow individuals to tell their own stories of their lived experience of HIV while at the same time ensuring such themes as experiences of the body, relationship to self and others, and access to care were covered through the interview. The interviews lasted approximately two hours and were conducted in a secure, confidential location of the participants' choice, either in their home or at the community organisation through which the person had been recruited. The interviews were taped

with the consent of the participants and transcribed in full. All information regarding participants' identities was removed from transcripts to ensure confidentiality. Ethical procedures were followed according to ethics protocol guidelines.

The first part of the interview was open ended and allowed the participant to tell their story. Most participants talked about their experience of living with HIV with a particular focus on how they were infected, how the diagnosis was experienced, and what it meant to come out about their diagnosis to others. Depending upon the way in which participants framed and told their stories of living with HIV several other sub-questions were asked in order to allow the participant to elaborate on key areas which included: the impact of living with HIV on the self and the body (health, the HIV experience, physical aptitudes, self-perception, body image, view of life, romantic and sexual life, *etc.*); social life (relationship with entourage, activities, professional life, material situation); experiences related to the intersection of HIV and ageing; experiences associated with stigmatisation and discrimination; and experiences accessing health and social services. The participants' stories were rich and complex and pointed to the multiple challenges of ageing and living with HIV.

Data analysis followed a phenomenological approach (Tesch 1990) in which interviews were transcribed and then analysed first as separate units to uncover statements in which participants described their experience. After each interview was analysed thoroughly and meaning units were noted in the margins of text, these units were then organised into theme areas relevant to participants. It is important to note that not all participants shared in the meaning attributed to a particular lived experience or phenomenon but rather, units of meaning were collected into themes that converged among participants and also those where divergence was indicated. This enabled us to locate points of shared meanings while also staying true to the multiple ways in which living with HIV was experienced by participants with diverse social locations and realities (*e.g.* by gender or sexual orientation or age at diagnosis). Data were then interpreted using both a descriptive method centred on a specific level (the specifics of a person's experience and the identification of a fundamental structure (a general description centred on the transsituational), in order to develop themes related to living the intersection of HIV and age. Saturation of the data was reached taking into account the initial objective of highlighting the essence of the lived experience of PLHIV₅₀₊. This analysis was conducted with the help of a qualitative data analysis software (NVivo).

Authenticity and validity principles of analysis were respected by implementing different methods throughout the research process (Creswell and Miller 2000). These included prolonged engagement in the

field (the principal investigator has been involved in research on HIV/AIDS for the past eight years while the co-investigator has been involved in research on ageing in gay and lesbian communities for 11 years), peer debriefing and member checking, primarily through the presentation of preliminary results with key informants including PLHIV₅₀₊ and practitioners working with this population.

Interviews were rich, diverse and complex. Participants spoke of the meaning of living with HIV and the intersectional impact of seropositivity and ageing on their experience of their body and the ageing process, their sense of self and identity, their relationships with others, work and economic challenges, and their ability to negotiate health care and social service systems. While we cannot present all their stories here, we will focus upon key issues which formed the essence of experiences across participants' stories.

Results

The responses of participants allowed for the identification of several central themes which constituted the essence of their experience of the intersection of HIV and ageing. On an individual level, participants spoke about their subjective bodily experience of what they defined as 'premature ageing' which seemed to have significant repercussions on self-perception. With respect to interpersonal relations, participants raised the issue of the repercussions of HIV status on their relationships with their children and grandchildren, the shrinking of their social network and the particular forms of stigma of HIV experienced when one is older. Lastly, on a structural level, the participants related their stories of socio-economic deprivation and difficulty associated both with work and the deterioration of their material situation.

The experience of premature ageing

Most of the participants reported feeling the signs of bodily ageing. They described several signs of ageing including a deterioration of their physical health, a decrease in energy and the deterioration of their appearance. According to these participants:

I don't see that I'm 60 years old but when I wake up in the morning, and then I get up, I see that I am 60 years old. Everything hurts. The joints are the most difficult. (female, 60 years old)

I will do sports for a shorter period of time, I will have to take a nap in the afternoon. I won't stay up as late. It happens sometimes that I'll go to a bar and after an hour I'm tired. This did not happen before. (male, 54)

According to their stories of bodily ageing, 'feeling' or 'getting' old was experienced prematurely and was attributed to the intersection of a normal biological process linked to age advancement, being HIV-positive, and feeling the effects of antiretroviral medications. Several participants talked specifically about experiencing a transformation of their appearance linked to these intersections of ageing and HIV status. Parallel to the physiological transformations due to age advancement, these changes were often linked to side-effects of antiretroviral medications and lipodystrophy, which gives the face an emaciated appearance and causes an increase of fat mass in certain parts of the body. As one female 53-year-old participant expressed:

I'm getting old, ugly and completely deformed, completely . . . But the fact is that it's not just HIV. Although I am very deformed by HIV in terms of lipodystrophy . . . I think that it's menopause that causes us to change all over. (But is it linked to HIV also?) Yes.

Regardless of how these physical transformations manifest, participants felt there was a gap between their chronological age and their age as perceived physically.

Because of HIV, the symptoms, it's the fatigue, then on top of it all after 50 we're not old but there are days when we feel old. We feel older than 50. And you don't feel like preparing meals or . . . doing anything! (female, 53)

The participants' responses revealed that premature ageing is generally interpreted through the lens of comparison between the norms or realities of those in the same age group as they are and the lived experience of ageing with HIV. For one of the participants recently diagnosed, the feeling of becoming old prematurely was exacerbated by the comparison of his current aptitudes with past aptitudes, his own representations relative to old age (namely a deterioration of physique) and the norms set by society regarding ageing.

You know, I can no longer do what I was doing before, I'm a little old man, practically retired . . . An old person in misery. But in essence it's still . . . 59 years, I am not old, old! I would be able to work if I still had the ability. (male, 59)

Another participant expressed this phenomenon of comparing oneself with other people of the same age who do not have HIV as follows:

We feel our body ageing faster. I look at my brothers who are 75 and 78 years old and in better shape than me. You know, like it or not, you see that your body has aged faster than them. (male, 60)

Regardless of how participants interpreted 'normal ageing', comparisons between themselves and others who did not have HIV (both those they knew and in society generally) was common and contributed to feelings of loss, negative self-concept and hopelessness.

The impact of HIV on intergenerational relationships

One of the major themes that emerged from the participants' stories concerned intergenerational relationships. Four participants interviewed were parents and/or grandparents. These participants spoke about their relationships with their children and/or grandchildren and, in particular, focused upon the ways in which their families responded to their HIV status both in terms of the impact of the stigma related to HIV and support provided by children and grandchildren. Several participants mentioned the difficulties that they faced in their relationships with their children with respect to the stigma associated with HIV. One difficulty concerned the issue of revealing their seropositivity to their children. The internalisation of stigma and the fear of rejection often drove participants to hide their diagnosis from their children. Two female participants said that they delayed revealing their diagnosis to their children because they were afraid of their reaction. One of the two, aged 63 years, reported having waited 14 years before revealing to her son that she was infected with HIV.

My son, it isn't that long ago that I told him. But what also happens is that the more you delay, the more difficult it is. . . . Then I asked myself: 'Ah! How is he going to take it?' I was afraid of being rejected, that he too would reject me. Because we heard about families who rejected their son when he told his parents. For me it was the opposite.

A second difficulty reported by participants concerns the negative attitudes that their children had of their parent once the diagnosis was revealed. These negative reactions occurred both just after the participant came out to their child regarding their diagnosis or in the years following. In the examples reported, the stigmatising attitudes of children were tied to their fear of contagion or the fear of the stigma being a reflection on them. One participant, recently diagnosed, reported that he was rejected by his son following the announcement of his seropositivity. In his thirties and himself the father of three children, his son refused to visit him during the first weeks following the diagnosis out of fear that his father could infect his own children. Another participant related a situation that was experienced several years after revealing her seropositivity to her son, which highlights the influence of the stigma related to HIV. She had been solicited to tell her story regarding her HIV infection to a newspaper and she had to give up having her photograph published with the article at the request of her son. The participant explains the attitude of her son in these terms:

Because he lives in a small town, and his in-laws, everyone comes from there, and they are people who don't really get out . . . , so he was afraid that maybe . . . his wife knows, but he would prefer that she didn't. (female, 63)

Another issue addressed by participants with respect to intergenerational relationships concerned the support provided by their descendants in light of their HIV status. The responses of participants highlighted a diversity of situations. For example, two participants said that they were satisfied with the support received from their children both from a practical and emotional point of view. One of these participants was a man who was initially rejected by his son but explained that their relationship became significantly stronger after his son was able to attend an information session on HIV provided by a practitioner. Two participants reported that their child offered to come live with them, one of them on a permanent basis and the other on temporary basis until he could find housing that suited him. However, it was primarily the emotional support and the existing emotional connection with their children that seemed to be appreciated by the participants. One participant who lives with her daughter explained:

It will be ten years in August that I am here, we get along very well. I cook and she cleans. We have a lot of fun together. (female, 63)

However, other participants expressed dissatisfaction with the support they received from their children. Two participants referred to a lack of dialogue with their children in relation to their HIV status. Both women, these participants expressed that their children were not ready to address the issue of HIV with them, as one explains: 'It's like a taboo subject'. This same participant felt a sense of isolation from her daughters which seemed to be exacerbated by her weakened physical health and her experience of ageing prematurely.

That's my fear, I told it to my daughters, one of them must at least call me more often, because I said: 'I don't want to die and then be in my apartment for one week because one of you hasn't called to inquire about me.' You know, to die alone. Listen, I'm getting older and it could happen at any time. (female, 53)

The relationships with grandchildren can also play an important role in supporting older individuals living with HIV. This was illustrated by the words of the participant who is a grandfather.

When I go to my son's, I will spend the weekend there, with the kids, and then I'm happy. The little one, he wakes me up in the morning so that I can take my medication. Because he saw my pillbox, and then he said to me: 'Why Grandfather?', and I said: 'If I want to be with all of you for a long time, I have to take them.' (male, 59)

Shrinking of the social network

One of the significant difficulties mentioned by the participants is the solitude and lack of friendships they experience on a daily basis. While some

reported feeling well integrated and having friends to count on, others experienced a shrinking of their social network with their advancement in age. This shrinking of participants' social network seems to be explained, on the one hand, by the loss of the circle of friends they had when they were younger, and on the other hand, by the difficulties in creating new social connections when living with HIV as they age.

Two gay men talked about the loss of their old social network in relation to their HIV diagnosis and the difficulties they faced in creating new friendships. One of the two lost his entire social network following the stigmatising attitudes with which he was confronted in the gay community once his entourage found out about his seropositivity. He brought up the difficulty he has had in recreating friendships since that time and the resulting tendency he has to isolate himself out of fear of being re-stigmatised. For the other participant, who is 50 years old, the crumbling of his social network was explained by the death of his friends who were living with HIV themselves.

My friends are . . . my friends, it's very limited because the last one died three years ago and I never re-established a circle of friends around me.

Another point, raised more by the women than the men, concerned the difficulty of PLHIV₅₀₊ to create new social relationships within the organisations intended for people living with HIV, given their advanced age. The words of one female participant highlighted this feeling of isolation that older people have in organisations that primarily draw a young clientele.

It's because these people are much too young. The organisations where I go, I'm the oldest person, there are others my age, but three-quarters are between 20 and 30, it's . . . It's more complicated. (female, 53)

Rejection by the older population

According to the participants' accounts, it appeared that the stigma linked to HIV is particularly evident among the older population. Several participants reported having experienced or feared experiencing this stigmatisation, as much within their relationships with their older entourage as within an institutional milieu. For example, two men talked about their experiences facing discriminatory attitudes of older people within their entourage. One explained that his aunt refuses to kiss him 'because she is afraid of getting AIDS'. A participant who was recently diagnosed reported having observed in his hometown that there was a difference in attitude between people of his age or younger and seniors with respect to HIV.

I saw people close to my age and I told them. You know, those who were my age understood. But it was mostly the oldest, you know . . . 70 and over, among others, how can I say, they don't accept it. (male, 59)

In relation to the problem of stigmatisation of HIV among the very old population, the participants also referred to the problem of discrimination of PLHIV in residences for seniors. Several people mentioned the fear of being subjected to attitudes of rejection in these institutions by other clients and/or practitioners because of the stigma associated with HIV. Furthermore, one participant raised the problem of discrimination which could be exercised by these institutions when admitting PLHIV₅₀₊. She related a story in which, as part of a self-help support group for people aged 50 years and over that she had previously belonged to, one of the members committed suicide in part due to the refusal of two seniors' residences to admit her because of her HIV status. Even though they had not confronted this situation, other participants admitted their fear of being subjected to similar discriminatory attitudes in seniors' residences.

But one day, when I get older and I am no longer autonomous, I will go to a place for seniors who are less autonomous. Probably there will be rejection there. And not rejected only by the nurse, by the people who work there, but by the people who live there. . . . Seniors often don't have a lot to do, so they talk behind other people's backs. So then if one of them finds out that someone has HIV, he can be rejected by everyone. (female, 63)

A difficult return to work

Other than one 50-year-old respondent who is registered with a government programme for a progressive return to work, all participants have stopped all work activities, three having taken their retirement and five having stopped working early for reasons linked to HIV. Several participants hoped to re-enter the workforce but have found it impossible to do due to the intersecting issues of health problems and discriminatory practices of employers. One participant recently diagnosed stated:

I worked for myself, I recycled metal and I made good money. And now today, from one day to the next, I am no longer able to do anything. It's hard. (male, 59)

In the case of those who had been diagnosed a long time ago, the difficulties associated with resuming work were often linked to the instability of their state of health. One 63-year-old female participant reported:

I never know. I can be . . . full of energy for five days and then on the sixth day I will sleep the whole day. So I can't have a job.

In parallel to the health problems, structural factors may also prevent the return to work after a long period of disability. Several participants

mentioned the discriminatory practices of employers in relation to both HIV status and ageing. One of the reasons for this discrimination, as stated by the participants, was the costs associated with the antiretroviral medications that must be assumed by the employer's insurance. The monthly cost of an antiretroviral therapy is more than a thousand dollars which is a major obstacle for seropositive people to access work, as expressed in the following account:

I don't know how they do it, the companies. Even if they do say that it's confidential, I noticed that all those who have insurance, when the time comes to be hired definitively: 'Ah! All of a sudden, they have a lack of work', and then they replace you with someone else. (female, 53)

In addition to these financial reasons, certain participants believed that employers also adopt discriminatory practices due to the stigmas associated with HIV and with age. From their point of view, being concerned with the intersection of ageing and HIV reduced the likelihood of being recruited by an employer. One participant explained:

Imagine a 50-year-old woman, and older, who is not on disability, who has HIV, and she has to return to the workforce! She might as well hang herself! She will not find a job! (female, 63)

A deterioration of living conditions

The material situation of the PLHIV₅₀₊ who participated in the study appeared to be largely influenced by the precarious work situations they faced. All participants received some form of government assistance or pension. Three participants collected a retirement pension, two benefited from disability pensions, while four others received allowances from a government social welfare programme. Several participants made mention of a deterioration in their living conditions that was tied to the decline of their financial situation. The first area of concern identified related to housing. Two participants who were homeowners (house or apartment building) were forced to sell their properties because of a loss of income related to no longer being able to work. Some participants also spoke about problems accessing leisure activities given their financial difficulties. All of these changes were experienced as being very difficult to live through, as reported by a 54-year-old male participant:

It [HIV] took a lot away from me. In terms of work and the income that goes along with it. I used to live in a four and a half, I went out a lot. I took trips every year. I am no longer able to pay for such luxuries. . . . And I didn't accept it, I didn't easily accept it! And I ask myself if I accept it even today. I have made progress but . . . I am still nostalgic for the time when I was comfortable. When I wanted to go to the theatre, a movie, travel. You don't forget that.

Another consequence of the financial difficulties faced by PLHIV₅₀₊ concerned access to paramedical services, such as dental care or optometry. As this type of care is not systematically covered by the *Régie de l'Assurance Maladie du Québec* (Quebec province's health insurance agency), people were sometimes forced to delay or give up care that was considered as important for their physical health. The same participant who experienced a significant decline in his material situation described a problem regarding access to essential care given the low amount of his disability pension and the fact that costs were not being reimbursed.

Me, I have [Can] \$871 per month. When I have certain needs, like glasses or dentures or foot orthotics, it's hell. I have to change glasses but I don't have the money so I have to wait. (male, 54)

It is important to emphasise that access to paramedical care proved to be difficult even when health problems experienced by participants were directly linked to complications from antiretroviral medication. One participant with lipoatrophy of the face explained that he could not benefit from treatment that would repair the damage caused by the side-effects of the antiretroviral treatments because it was not covered by public health insurance.

It must be three to five years since I've had my cheeks filled . . . Now there are no more subsidies for the product so you have to pay for it. It comes to more than \$1,000! In addition to the doctors who are now \$250 for every visit. For me it's at least six to eight . . . So it's a lot of money for someone on social assistance. (male, 60)

Discussion

The results of this research highlight some of the many challenges faced by PLHIV₅₀₊ resulting from the intersection of HIV and ageing. One critical point concerns the subjective perception of the premature physical ageing of PLHIV₅₀₊. Participants described in detail the role of the lived bodily reality of HIV in the construction of self as one who is *becoming prematurely old*. Similar to the general ageing population (Vannienwenhove 2009), PLHIV₅₀₊ perceive their ageing through changes that are registered in the body (state of health and physical abilities), appearance and energy, and use a comparison process to interpret these corporal signs of ageing. However, contrary to the general population (Vannienwenhove 2009), for whom this mechanism generally has a valorising effect, among PLHIV₅₀₊ this comparison to others of the same age without HIV contributes to feelings of fear, hopelessness and shame/stigma, producing an invalidating effect. This divergence could be explained by the gap between the chronological age of people, to which they associate certain norms relative

to physical aptitudes and appearance, and the physical age that they feel as a result of living with HIV and its consequences. PLHIV₅₀₊ have two contradictory identities, one based on objective age considered socially to be younger, and the other, which emanates from the perception of a body that is deficient and ageing. This discrepancy evokes the mask of ageing problematic as introduced by Featherstone and Hepworth (1991), who refers to the tension between outward appearance or functional capacities and inner identity, experienced by elderly people. For PLHIV the mask of ageing problematic is experienced earlier in their life.

An important point emerging from the research relates to the reality that participants largely described consequences of living with HIV and long-term effects of medication as contributing to negative self-perception of ageing, rather than as solely the negative effects of living with HIV. What this might mean is that internalisation of ageism has a more profound impact upon self-perception and bodily accounts of identity than HIV status. At minimum it calls into question how self-identity and self-esteem are addressed with the older population of PLHIV. Programmes and interventions with younger cohorts which address issues of stigma and shame related to HIV status may not be appropriate for those older PLHIV who are also dealing with the losses attributed to ageing processes and stigma associated with ageism and for whom ageing as a phenomenon cannot be separated out from living with HIV.

A second issue raised by this research concerns the problem of the reactions of adult children to the seropositivity of their parents. Quantitative research has highlighted the lack of relationships and support to parents from the children of PLHIV₅₀₊ (Karpiak, Shippy and Cantor 2006; Shippy and Karpiak 2005). The results of our study demonstrate that while certain participants feared rejection by their children or were subjected to their negative attitudes with respect to their seropositivity, others (and sometimes the same person at two different times) benefited from strong support from their children. Our results suggest that participants who received the most support were those whose children accepted their seropositivity. Conversely, stigma of HIV seemed to lead some children to eclipse the needs of their parents and to withhold the support that they would otherwise have provided. In developing countries, intrafamilial solidarity appears to be more important, since it has been observed that many older adults take care of family members with HIV (Hosegood and Timaeus 2006; Knodel *et al.* 2001, 2003; WHO 2002; Wilson and Adamchak 2001). One might yet wonder if the same solidarity would arise from adult children toward elderly parents living with HIV. Studies have highlighted the impact of the stigma of HIV on grandparents who are caring for grandchildren with HIV in North America and in developing countries (Poindexter 2004;

Knodel *et al.* 2010; Ogunmefun, Gilbert and Schatz 2011; WHO 2002); however, none has addressed the impact of the stigma on children of older PLHIV. Our study revealed that children may fear that the stigma their parent bears will have repercussions on them. This phenomenon is described as ‘courtesy stigma’ by Goffman (1968). It would seem important, therefore, to explore in greater depth, the phenomenon of the management of stigma among the descendants of older PLHIV and the repercussions this stigma has on their relationships. Moreover, our study highlighted the moral support resulting from the grandparental role of one participant. Although this point is raised by Keigher, Stevens and Plach (2004), the issue remains largely unexplored and points to the need to more systematically examine the role of intergenerational relationships in the lives of older people living with HIV as they age.

Another issue related to the experience of stigma among this population concerns the real lived and anticipated fear of stigma faced within the senior population generally and the institutions that serve this clientele. Although several research studies conducted in Western countries have raised the problem of stigmatisation experienced by PLHIV₅₀₊ (Emler 2006a, 2006b, 2007; Karpiak, Shippy and Cantor 2006), none has stressed the reality that this phenomenon is more evident among the very old population. That phenomenon can nonetheless be linked to the results of studies carried out in developing countries where older adults are seemingly less well informed about HIV than young adults (Hillman 2008; Im-em *et al.* 2002; Knodel, Watkins and VanLandingham 2003), and less accepting of HIV-positive persons than younger adults (Ford and Chamratrithirong 2009). This problem is not without its consequences because PLHIV who experience premature ageing risk losing their autonomy at a younger age than the general population and therefore needing to be placed in residences for seniors. The risk of stigmatisation for PLHIV in seniors programmes and residences has been previously raised by Wyatt (1996) who reminds us of the reticence of institutions to admit people with a history of drug addiction or who are openly gay (Brotman, Ryan and Cormier 2003). This reticence to provide care for fear of contagion or the taboo surrounding sexuality and risk behaviours (Altschuler, Katz and Tynan 2004; Wallach 2008), certainly contributes to structural discrimination in the form of exclusion and marginalisation within seniors programmes and services, particularly residential care. Given that a number of our participants spoke of their fears of living in communal environments, the potential exists among PLHIV₅₀₊ that they will delay or refuse much needed support in order to reduce exposure to discrimination. HIV among older populations is an issue which has long been ignored in geriatric and gerontological settings and services. This study points to the need to redress this gap.

Social integration was also closely linked to the problem of stigma among PLHIV₅₀₊. Writing in the field of social gerontology has long emphasised that ageing can be accompanied by a progressive decline of social networks (Aronson and Neysmith 2001; Lavigne and Fortin 2007). Our study demonstrated that isolation is a common problem for PLHIV₅₀₊. Gay men may have a unique experience of this phenomenon due to several factors including the potential reality of loss of friendship networks primarily composed of other gay men living with HIV. This corroborates the results of Poindexter and Shippy (2008) with respect to the fragility of the social networks of PLHIV₅₀₊. This reality may be exacerbated by particular forms of ageism within gay communities that already contribute to invisibility and marginalisation of older gay men in communal spaces and within social programmes sponsored by LGBT community organisations (Brotman, Ryan and Cormier 2003). With respect to the heterosexual women who participated in the study, it seems that their isolation is related more to the absence of seniors in organisations for PLHIV, which echoes the results of Solomon (1996). As other authors have concluded (Nichols *et al.* 2002; Shippy and Karpiak 2005), this weak representation of seniors could be explained by the lack of programmes for an ageing clientele in organisations for PLHIV which points to a lack of recognition of the needs of the senior population in the HIV-specialised milieu.

On a socio-economic level, our research revealed that PLHIV₅₀₊ experience work challenges in relation to both HIV status and age. These are tied to the repercussions of their physical health and also to discrimination practised by employers. Problems of discrimination linked to HIV, on the one hand, and to age on the other hand, hinder access to employment, as highlighted by different studies (Dray-Spira *et al.* 2007; Duncan 2003; Finkelstein, Burke and Raju 1995; Malcolm *et al.* 1998; McCann and Giles 2002). In the case of PLHIV₅₀₊, the intersection of these two problems increases the risk of exposure to discrimination in the workplace. Our research demonstrated that early work cessation due to health problems and the impossibility of returning to work have direct repercussions on the economic situation of PLHIV₅₀₊. Generally, the income of seniors tends to be lower than the rest of the population (Cheal and Kampen 1998; Government of Canada 2005). To the extent that the income of PLHIV₅₀₊ comes from social assistance, a disability pension or retirement pension, they are even more at risk of poverty than the general senior population. This reaffirms that a drop in socio-economic status experienced by participants is most closely related to the premature interruptions of work activity due to the HIV infection, a reality which cuts across social location (such as gender and age). The research results

highlighted that the low incomes of PLHIV₅₀₊ could impede their access to resources that are essential to their quality of life, such as paramedical care. This situation proved to be particularly problematic for a population whose health needs, which are already significant, increase with advancing age. Beyond the problem of not having access to a sufficient income due to HIV status, it is possible to attribute the difficulties associated with access to care for PLHIV₅₀₊ to the absence of measures for social protection and programmes offered by the health and social services network to respond to the needs of the ageing population of PLHIV (Lebouché, Wallach and Lévy 2008; Wallach 2008). This must be identified as a form of institutional discrimination. One can only regret the absence of research on the socio-economical situation of older adults living with HIV in developing countries, which is presumably even more of an issue than for those who live in economically advanced countries. The scale of the HIV pandemic in the developing world threatens to deprive seniors of material support traditionally provided by their adult children, particularly if those children are also affected by the disease. This situation can lead older adults living with HIV to attempt to provide financial support to other family members, at the expense of their own health and access to antiretroviral treatments. Furthermore, according to Wilson and Adamchak (2001), structural changes occurring in developing countries undermine support to older adults living with HIV, by driving younger generations to migrate to urban centres, thus leaving behind their elderly parents. PLHIV₅₀₊ are therefore deprived of their primary and most traditional form of informal material support. The socio-economic situation of older adults with HIV remains a largely ignored but vital field of research to be carried out in a global context. Only then can nations around the world better assess the needs of this population.

Limitations

Despite its original contribution to the literature on the phenomenon of PLHIV₅₀₊ in Canada, this study has certain limitations primarily due to its exploratory nature. While this article revealed the many problems faced by PLHIV₅₀₊, preliminary results may be confirmed through interviews with a larger sample of participants. In addition, all participants were recruited through community organisations in the Montreal area which resulted in a lack of ethnic, cultural and geographic diversity among participants.

Conclusions

This exploratory research highlighted the lived experience of PLHIV₅₀₊. It focused upon the phenomenon of the intersection of ageing and HIV. Through the rich and diverse stories of nine individuals, we were able to explore the central themes of the body, social relationships, work and economic realities facing this population. PLHIV₅₀₊ represent a population that is particularly subject to psycho-social and economic difficulties. Through their stories, participants shared how living at the intersection of HIV and ageing shapes their lives and significantly limits their possibilities of economic and social security. Even though some of the problems faced by PLHIV₅₀₊ are related to the experience of corporal changes and a deterioration of physical health, our research was able to highlight that most are attributable to societal and structural factors underlying the stigma of HIV and ageing. The results also highlight the fact that PLHIV₅₀₊ demonstrate considerable agency as they negotiate their relationships, address issues of economic insecurity and face health challenges. These results confirm the urgency for those in the fields of health, HIV studies and gerontology to address the issues and realities facing this population both in Canada and around the world. Research in developing countries has recently suggested moving from the study of those *infected with HIV* to those *affected by HIV* (Williams, Knodel and Lam 2010). Given that there is a paucity of research in the developing world on older adults infected with HIV, this suggestion seems premature. In fact, it is our suggestion that research, both in Canada and around the world, must address the complex reality of living with HIV through the comprehensive study of those infected with *and* affected by HIV. There is much to learn from older adults living with HIV. Taking an international perspective which documents the situation of older PLHIV in both developed and developing countries will enable researchers and policy makers to better grasp the complexity and diversity of the lived experiences of PLHIV₅₀₊, and to develop new domains of intervention in order to redress discrimination and improve quality of life.

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NOTES

- 1 Fifty years of age and older has been established in the scholarship on HIV/AIDS as the accepted cohort of those considered within the category of 'seniors'. This is considerably younger than the commonly used '65 years of age and older' in the general gerontology literature. However, medical research has established that HIV accelerates the ageing process thus warranting a consideration of those 50 years of age and older as a distinct and unique cohort for consideration in both research and intervention strategies.
- 2 The current project defines health from a broad perspective that incorporates the physical, psychological, emotional, social and spiritual components that contribute to health and wellbeing. The lived experience of being a PLHIV₅₀₊ necessitates a broad view of health in which issues such as coming out, locating community and managing discrimination are contextualised and understood as both health and mental health issues. Utilising this perspective facilitates the integration of an analysis of the health impacts of marginalisation upon the lives of PLHIV₅₀₊ and the necessity of addressing physical, emotional, social, spiritual and psychological assistance when articulating recommendations for change.
- 3 Intersectionality theory is derived from the broader writing on 'critical race theory' (Crenshaw 1995; Delgado 1995), although anti-racist feminist literature of the same period also refers to this concept (Bannerji 1995; Bishop 1994; Stasiulis 1990). Formed for the most part by legal theorists of colour, critical race theory addresses the law's treatment of indigenous peoples and people of colour and the role law has played in maintaining social domination and subordination. Intersectionality is based upon the premise that intersections of oppressions cannot be captured wholly by looking at the separate identity dimensions of experience (Anthias, Yuval-Davis and Cain 1992; Caldwell 1991; Grillo 1995). Feminist and critical race scholar Kimberlé Crenshaw (1995) brought forward theorising about the particular burdens placed on black women in the USA, and coined the term 'intersectionality', which has since gone on to be incorporated as an integral aspect of a critical, anti-oppressive framework (Mullaly 2002). While the existence of distinct categories of oppression (such as race, class, gender, sexuality, ability, *etc.*) is acknowledged, they cannot be essentialised or separated from each other (Brotman and Ryan 2004; Crenshaw 1995; Mullaly 2002). Sherene Razack (1998: 12), citing Patricia Hill Collins and Trinh T. Minh-ha, describes the concept of *interlocking systems of domination* as differing from *intersectionality*, emphasising the importance of examining the interlocking effects of race, class, gender, disability and sexuality in a historical and site-specific way. Therefore, the existence and maintenance of systems of domination, across categories of oppression, are dependent on each other, producing complex, hierarchical and symbiotic social relations (Fellows and Razack 1998; Razack 1998). Intersectionality considers that the different forms of discrimination should not be understood in terms of their cumulative dimension but rather in their articulation, their interaction or their intersection.
- 4 Individual networks of meanings refers to 'personal trauma, life stresses, fears and expectations about illness social reactions of friends and authorities and therapeutic experience' whereas network of signification of a society refers to 'metaphors associated with a disease and ethnomedical theories, basics values and care patterns' of a society (Good and Delvecchio Good 1980: 176).

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Address for correspondence:

Isabelle Wallach, Département de sexologie,
Université du Québec à Montréal,
Montréal, Québec, Canada.

E-mail: wallach.isabelle@uqam.ca