# THE CURRENT STATE OF KNOWLEDGE OF MENTAL HEALTH ISSUES SUFFERED BY NORTH AMERICAN ADULTS LEARNING TO LIVE WITH HIV/AIDS DIAGNOSIS AND EXPERIENCING STIGMA IN ACCESSING HEALTHCARE SERVICES

By

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#### **Abstract**

For individuals living with Human Immunodeficiency Virus or Acquired Immunodeficiency Syndrome [HIV/AIDS], the long-term toll on their physical health is well-documented. However, adverse impacts on their mental health are not as widely publicized, yet can be even more challenging for infected individuals to deal with. In North America, if HAART or other treatments are started early enough, most of those "death sentences" have been commuted into a "largely manageable chronic disease" (Fang, Vincent, Calabrese, Heckman, Sikkema, Humphries and Hansen, 2016, p. 2). This literature review seeks to answer the research question "What is the current state of knowledge regarding the serious mental health issues suffered by adult patients diagnosed with and learning to live with HIV/AIDS and how social workers can help meet their needs and challenges?" Key findings include the widespread suffering of People Living with HIV/AIDS [PLHA] caused by HIV-related stigma (enacted, internalized and anticipated), by medical professionals and others. Depression, increased life-stress, HIV-Associated Neurocognitive Disorder [HAND], heightened anxiety and increased high risk behavior (such as engaging in unprotected sex) are the main mental health issues and challenges resulting from HIV-related stigma. Past researches recommends taking a comprehensive holistic approach, which includes but is not limited to additional anti-stigma training for future and current social and health care workers, HAND-testing, individual HIV-case management and stronger advocating for HIV-positive clients.

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#### **List of Acronyms**

AIDS – Auto-Immune Deficiency Syndrome

ANI - Asymptomatic Neurocognitive Impairment

ART – Anti-Retroviral Treatment

cART – Combination Anti-Retroviral Treatment

**CRT** - Cognitive Remediation Therapy

CSWE - Council on Social Work Education

FDA – Food and Drug Administration

GBM – Gay and Bisexual Men

HAART – Highly Active Anti-Retroviral Treatment

HAD - HIV-Associated Dementia

HAND – HIV-|Associated Neurocognitive Disorder

HIV – Human Immunodeficiency Virus

HRQoL - Health-Related Quality of Life

HSF – Health Stigma Framework

IET – Intergroup Emotions Theory

LGBT - Lesbian, Gay, Bisexual and Transgender

LGBTQ – Lesbian, Gay, Bisexual, Transgender, and Queer (or Questioning)

LGBTQ2S – Lesbian, Gay, Bisexual, Transgender, Transsexual, Queer, Questioning, and 2-Spirit

MND – Mild Neurocognitive Disorder

NNRTIs – Non-Nucleoside Reverse Transcriptase Inhibitors

NRTIs – Nucleoside Reverse Transcriptase Inhibitors

PLWH – People Living with HIV

PLWHA/PLHA – People Living with HIV/AIDS

PTSD – Post-Traumatic Stress Disorder

PWHA – People with HIV/AIDS

SDI – Socially Disadvantaged Individuals

SDO – Social Dominance Orientation

SDOH - Social Determinants of Health

SI – Social Identity

ST – Syndemic Theory

STLE – Stressful or Traumatic Life Event

SWCoC - Social Workers Code of Conduct

UNAIDS – Joint United Nations Programme on HIV/AIDS

#### 1. Introduction

For individuals living with HIV/AIDS, the long-term toll on their physical health is well-documented. However, adverse impacts on their mental health are not as widely publicized, yet can be even more challenging for infected individuals to deal with as this report will document. Prior to the development of highly active antiretroviral therapy [HAART] introduced in 1996, contracting the HIV virus was considered a certain "death sentence" because it would eventually advance into AIDS, leaving the body too weak to fight back (Stringer et al., 2016, p. 115; Lassoued, Gobert & Spano, 2015, p. 541; Trickey et al., 2017, p. 349). This deadly virus enters the body and destroys T cells, which are necessary in the fight against infection, thereby lowering the life-expectancy of an untreated patient with HIV/AIDS to just three years (Panigrahi, 2017). Anti-HIV treatments, including nucleoside reverse transcriptase inhibitors [NRTIs] introduced in 1987, HAART (an advanced NRTIs treatment) and non-nucleoside reverse transcriptase inhibitors [NNRTIs] also introduced and FDA approved in 1996, were the critical turning point patients, their loved ones, and their medical specialists had been waiting for (Lassoued et al., 2015).

Unfortunately, in 2015, the "global HIV/AIDS pandemic persists" as 2.1 million new cases of HIV infections and another 1.1 million AIDS-associated deaths were reported worldwide (Steinbrook, 2016, p. 1139). In 2014, UNAIDS reported that the vast majority of the new cases and deaths occur in developing countries with inadequate health care systems, shortages of advanced treatment drugs, and too few trained medical personnel for the number of people they must treat (p. 6). However, in North America, if HAART or other treatments are started early enough, most of those "death sentences" have been commuted into a "largely manageable chronic disease" with patients surviving for increasingly longer periods of time

(Fang et al., 2016, p. 2; UNAIDS 2014; Stringer et al., 2016). Thanks to the new treatment regimens, infected individuals now suffer less from the physically debilitating effects of HIV, which can help prevent the onset of AIDS (Panigrahi, 2017). In fact, with treatment, most North American patients infected with HIV can now expect to survive for many years if they are careful to follow prescribed treatments and associated health strategies. The UNAIDS Gap Report (2014) even states that "a person on HIV treatment in a high-income setting now has nearly the same life expectancy as a person who does not have the virus" (p. 1). One recent study involving 88,504 patients with HIV found mortality rates among North American HIV patients began to decline, and life expectancies increased among those who began their Anti-Retroviral Therapies [ART] in 2008-10 (Trickey et al., 2017). Several of the studies, later discussed in detail, involve interviewing and studying long-term HIV/AIDS survivors who have already lived with this disease for fifteen or more years (Emlet, Harris, Brennan, Furlotte and Pierpaoli, 2017; Fang et al., 2015; Ironson, Fitch, and Stuetzle, 2017).

As can be imagined, anyone diagnosed with a chronic disease for which there is no cure, with only HAART and other treatments to control the worst physical effects of the viral infection will experience some adverse reaction, such as depression or elevated life stress, after receiving such bad news (Bengtson et al., 2015). The shock of such a diagnosis can easily result in serious emotional and mental health issues as a result of having their world turned upside-down.

Fortunately, they can seek out social workers who are specially trained in helping people with HIV/AIDS find the mental health support they need to deal with their depression, find treatment options, and/or advocate against any stigma they may experience. Well trained social workers working with HIV-positive individuals can make a holistic assessment of each client diagnosed with HIV/AIDS to better understand their specific situation.

This viral disease, though, continues to infect new victims; and learning to cope with life after being diagnosed as HIV-positive remains a difficult mental health challenge for individual patients. According to Fang et al. (2016), in North America, approximately half of all HIV/AIDS cases involve older people (ages 50+ years). Compared to younger patients, middle aged and older adult HIV-positive individuals are more likely to experience HIV-related stigma among their peers (Earnshaw, Lang, Lippitt, Jin & Chaudoir, 2015). They are also more likely to have fewer social supports and experience more "co-morbid psychiatric conditions" (Fang et al., 2016, p.2).

Their psychosocial assessment must address each client's overall mental, emotional and physical needs, as well as identify challenges they face and successes they can build upon (Lynch, 2016). In North America, for the last three decades, the social workers working with HIV-positive individuals have been on the front lines of this pandemic, often taking the lead when it came to "developing and implementing HIV-specific psychosocial service programs" (Lynch, 2016, p. 418). The social workers working with HIV-positive individuals developed programs that include HIV case management, housing, mental health needs, client advocacy and empowerment, end-of-life care treatments, and ways to reduce risk of infection and spread of this disease (Lynch, 2016).

What is the current state of knowledge regarding the serious mental health issues suffered by adult patients diagnosed with and learning to live with HIV/AIDS and how social workers can help meet their needs and challenges? The purpose of this literature review is to critically analyze recently published (2014 to September 2018) and relevant literature from multiple disciplines to present the latest findings about the most common and serious adverse mental health impacts, such as depression, higher life stress, anxiety, and increased high-risk

behaviours, among individuals living with HIV/AIDS. The latest developments, such as new ART drugs and improved psychosocial programs, in the treatment, management, and prevention of such mental health challenges to promote higher quality of life by reducing the stigma suffered by HIV patients will also be identified, discussed and analyzed. By collating and organizing the latest research on HIV-related mental health impacts, different stakeholders such as government agencies, HIV/AIDS organizations, and concerned individuals will have a clearer idea of potential issues and formulate possible solutions or therapies for treating the mental health needs of HIV patients.

## 1. Methodology

To develop this thematic literature review, extensive use of the Google Scholar search engine and the University of the Fraser Valley database were made. The online searches employed combinations of key search terms such as "HIV/AIDS", "stigma", "mental health issues", "emotional challenges", "social workers", "North America", "Canada", "depression", "discrimination", "treatments", "HAART", "NRTIs", "NNRTIs", "health outcomes", "risk behavior", "increased stress anxiety", "aging", "life expectancies", and "people living with HIV (PLHIV)". In order to limit the chronological scope of this literature review, I decided to focus on the latest research findings from 2014 to September 2018, roughly the last five years. Most of the thematic literature review focused on analyzing peer-reviewed research articles from a wide range of journals such as *Annual Review of Sociology, Teaching Sociology, Aging & Mental Health, AIDS and Behavior, AIDS Care, AIDS Research and Treatment, Journal of Health Economics, Lancet HIV, AIDS, Journal of the International AIDS Society, Psychosomatic* 

Medicine, Current Opinion in HIV and AIDS, Journal of Affective Disorders, and AIDS

Education and Prevention. Government sources such as the US Census Bureau and UN AIDS

were also included in this literature review, as are subject-specific books, such as Panigrahi

(2017) chapter on AIDS in Panda and Padhi (Eds.) Human Diseases reference book.

Hundreds of online journal articles were found using various combinations of key search term, but a multi-stages selection process was used to eliminate obviously irrelevant studies and identify potentially strong sources. My preliminary search involved identifying only those articles with promising titles (about mental health issues related to HIV and North American studies). Their links were then opened and the abstracts read. Then, if the abstracts proved relevant to this paper's subtopics, the rest of the article was quickly scanned to ensure the articles' themes and content would be useful. Those articles with relevant data on North American HIV studies, allowed access without charge, and filled gaps in the literature search were chosen for inclusion in this paper. The chosen articles were then read more carefully to identify useful, relevant facts and findings which could be organized and added to this literature review. These academic sources primarily employed a mix of quantitative and qualitative methods, ranging from empirical analysis of HIV/AIDS data sets to self-reporting surveys and questionnaires/interviews, as well as several literature reviews on past HIV-related research.

Despite gaps in the literature, linkages between the various themes and sub-topics were also identified to help organize the literature review.

#### 2. Findings

Common themes were found in several research papers on HIV and mental health issues, which helped determine main themes and subtopics for this literature review paper. The first

main theme identified from the analysis of past HIV studies is HIV/AIDS Stigma and Discrimination, which includes stigma-related theories such as Earnshaw & Chaudoir's (2009) Health Stigma Framework (HSF), Social Dominance Orientation (SDO) Theory by Sidanius and Pratto (1999), Social Identity (SI) Theory by Tajfel and Turner (1979), Intergroup Emotions Theory (IET) by Mackie, Devos and Smith (1993) and Singer's (1995) Syndemic Theory (ST). HSF, SDO, SI, IET and ST are the included under their own secondary subtitles and their theoretical frameworks and how they apply to HIV-related stigma and discrimination are explained. The second main theme is Depression and Heightened Anxiety, which often results from being stigmatized and discriminated against. When similar HIV-related stigma and mental health themes were found in multiple articles, information about those topics was gathered under their respective thematic sub-titles, such as Increased Life Stress, HIV-Associated Neurocognitive Disorder (HAND), and Increased Life-Risk Behaviours, to be later organized, collated, and expanded upon.

#### 3.1 HIV/AIDS Stigma & Discrimination

Stigma is an attribute "devalued by society and, if the stigma is known to others, leads to the dehumanization of the person who possesses this attribute" (Talbot, 2014, p.1). Compared to people diagnosed with other ailments and diseases, such as Alzheimer's, cancer or heart disease, there is a widely held view that HIV-diagnosed individuals are "more responsible for their stigmatized identities" (Talbot, 2014, p. 26). The premise behind this "possible responsibility" is that many HIV-diagnosed patients contracted the virus through "controllable (e.g. promiscuous sexual behavior)" modes of transmission and becoming infected is a direct result of their own actions or poor decisions (Talbot, 2014, p. 26). Studies have found that homophobia is often at least partly the root cause behind some HIV-stigma as "people with HIV/AIDS [PWHA]

continue to be marginalized and gay men... disproportionately affected by the disease" (Pelts, Rolbiecki & Albright, 2014, p. 136). On the other hand, there is considerably less anger or stigma aimed at, and significantly more pity felt towards patients who have contracted the virus "via uncontrollable means (e.g. blood transfusion)" (Talbot, 2014, p. 26). Despite decades of public education about HIV/AIDS, the stigma associated with contracting this disease continues to persist in most societies, threatening the physical and mental health of "People Living with HIV" (PLWH) or "People Living with HIV/AIDS" (PLWHA or PLHA) (Earnshaw et al., 2015, p. 2; UNAIDS, 2014, p. 6; Edmonds, Moore, Valdez & Tomlinson, 2015, p. 238).

Physically, being stigmatized or having anticipation of HIV discrimination has been found to result in more severe HIV symptoms (Turan et al., 2017). The symptoms elevated by HIV-stigma (either actual and anticipated) include fatigue, gastro-intestinal pain, weight gain/loss, numbness and bruising or internal bleeding) and poorer physical health outcomes (Earnshaw et al., 2015; Turan et al., 2017; Rueda et al., 2016). Rather than focusing all their energies towards fighting the virus, HIV-stigmatized patients must deal with individuals, sometimes even health care professionals, who treat them differently because of their HIV diagnosis. Rueda et al. (2016), for instance, found that "people who experienced HIV-related stigma were 21% less likely to access or use health and social services" (p. 9). Missing doctor's appointments or HAART treatments as a reaction to being HIV-stigmatized can have potentially harmful physical health outcomes.

Mentally, the harm from such stigmatization manifests itself in a wide range of mental health issues, from increased anxiety and stress, all the way up to suicidal thoughts and behaviours (Turan et al., 2017; Talbot, 2014; Ozra et al., 2015; O'Donnell et al., 2016). Being discriminated against for something the individual cannot change is difficult enough for a

healthy person to deal with. Discrimination leading to stigmatization of someone fighting against a serious virus infection such as HIV is socially immoral and, among health care professionals, it is professionally unethical as it is their job to promote positive health outcomes, not cause their patients more suffering (Wagner, Girard, McShane, Margolese, & Hart, 2017; Wagner, Hart, McShane, Margolese, & Girard, 2014). After all, HIV-related stigma has been found to be associated with higher levels of depression and other mental health issues (Rueda et al., 2016). If HIV-stigmatized patients avoid accessing social services out of fear of being treated as social pariahs, they will not get the advocacy help or access to psychosocial programs to help them overcome these mental health issues associated with HIV-related stigma (Lynch, 2016).

Sadly, in a systematic review of 64 studies published between 1996 and 2013, researchers found that HIV-related stigma is a global social phenomenon occurring in a broad range of social domains, including documented cases of discrimination in healthcare environments (Rueda et al., 2016). Enacted stigma from some healthcare providers include "denial of care or treatment, HIV testing without consent, confidentiality breaches, negative attitudes and humiliating practices by health care workers" (Rueda et al., 2016, p. 2). According to UNAIDS (2014), mistreatment or even possible human rights violations of HIV-diagnosed patients by health-care providers and professionals is not a rare occurrence. How terrible it must be for patients already dealing with the life-altering, life-threatening diagnosis of being HIV-positive to suspect or know that their own doctors or nurses harbour prejudicial attitudes towards people with this disease (Chambers et al., 2015). These are the medical professionals the patients depend on to treat the disease, so the sense of betrayal and helplessness can be significant in terms of impact.

One Canadian study conducted among medical and nursing students in universities across this nation found that HIV-related fear and prejudice remain serious issues in Canada's health

care system. Wagner et al. (2014) state "HIV-related stigma is especially problematic within the health care system" (p.2). The researchers explain how patients feeling stigmatized by a doctor, nurse or other health care provider may suffer adverse impacts on the care they receive, their quality of life or their engagement in the health care process. In their study, Wagner et al. (2014) surveyed 234 health care students across Canada, ranging in age from 18 to 41 years, who voluntarily agreed to complete an online questionnaire. Among the survey participants, 45.1% (N=101) were completing their nursing program and 54.9% (N=123) were in a medical program. The vast majority participants self-reported serious concerns about working around or treating HIV-positive patients, including feeling "uncomfortable", "worry about contracting HIV from HIV-positive patients" and "would rather not come into physical contact with HIV-positive patients" (Wagner et al. 2014, p.8).

Some of their discomfort or reluctance to treat or interact with HIV-positive patients may be due to other prejudices the participants hold. According to Orza and collegues (2015), for HIV-infected patients with multiple socially disadvantaged identities (SDIs), such as members of visible racial minorities, people in poverty, people who have substance abuse issues, and people who are part of the Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) community, are more likely experience HIV-stigma associated mental health issues (p. 7). If so many future health care workers express these types of stigmatizing reactions at the thought of treating HIV-positive patients or discriminate against SDI patients, much work is apparently necessary to reverse this prejudice among Canadian medical and nursing students and professionals. Understanding the overlapping stigmas, including homophobia, racism, and stigma against drug addicts or sex workers, held by health care students, trainees, and professionals can help medical and nursing schools improve their programs to include more stigma-informed training for health

care trainees (Wagner et al., 2017). Such changes will hopefully result in more effective and compassionate care for HIV-positive patients and reduce the stigmatization by Canada's health care professionals.

## 3.1.1 Earnshaw & Chaudoir's (2009) Health Stigma Framework (HSF).

One well respected heuristic model for analyzing stigma effects is Earnshaw and Chaudoir's (2009) Health Stigma Framework (HSF), developed in 2009, which identifies three main HIV-related stigma mechanisms (Turan et al., 2017). The three HSF stigma mechanisms are: enacted stigma; anticipated stigma; and internalized stigma. Enacted stigma is when the HIV-positive patient experiences actual acts of discrimination, prejudice and devaluation from others due to their illness (Turan et al., 2017). Studies show that enacted stigma is more common in cases of "multiple (concurrent) stigmatized identities" or multiple SDIs, which explains why people who are LGBTQ2S who contracted HIV/AIDS experienced "double the amount of stigma than a heterosexual person with HIV" (Talbot, 2014, p. 25). Similarly, HIV-positive ethnic minorities experience more enacted stigma compared to their Caucasian counterparts (Talbot, 2014). Some research, moreover, suggests that enacted stigma is more common in small urban and rural settings, where public fears and prejudice result in acts of HIV/AIDS related discrimination causing adverse mental health impacts (Kalichman, Katner, Banas & Kalichman, 2017). Public education efforts are often less apparent in lower-population density regions so higher levels of enacted HIV stigma is predictably higher in rural America versus big cities such as Los Angeles, CA, for instance.

Anticipated stigma, as the name suggests, is when the patient believes others will treat him/her differently due to his/her HIV-positive status (Earnshaw et al., 2015). Again, Kalichman

and colleagues (2017) claim that in many rural areas in the United States, "perceived community stigma[s]" are more common than in densely populated urban settings (p. 518). Sadly, the mental health effects of anticipated stigma include fears over the reaction of others to a positive HIV diagnosis causing some people to postpone testing for HIV or not adhering to antiretroviral therapy (Rueda et al., 2016; Kalichman et al., 2017). Acting on (or inaction due to) anticipated stigma greatly increases the likelihood and frequency of receiving a later stage HIV infection diagnoses, increased difficulty to treat the disease, higher mortality rates, and higher chances the fearful individuals have infected other people (Rueda et al., 2016; Kalichman et al., 2017).

Internalized stigma refers to the patient's acceptance of such adverse societal responses and applies those fearful, hateful, prejudiced perceptions to themselves. Internalized stigma is often what leads to depression and other adverse mental health effects (Turan et al., 2017; Rueda et al., 2016). Kalichman and colleagues (2017) mixed qualitative/quantitative research (N = 696) concluded that "individuals living in small-urban and rural areas indicated greater internalized AIDS-related stigma" (p.523). Their findings of lower internalized and enacted stigma in high-density urban settings compared to rural areas are consistent with past research findings (Gonzalez, Miller, Solomon, Bunn & Cassidy, 2009).

According to UNAIDS (2014), being stigmatized can also lead to discrimination when trying to obtain housing, jobs, and other resources. Potential landlords and employers, upon learning that the applicant is HIV-positive will often act (illegally) upon their subconscious fears and prejudices against people with HIV/AIDS, and find excuses not to rent them the apartment or hire them for the open job position. Individuals who suffer from enacted stigmatization experience less control over what is happening in their lives, as they are devalued and ignored by others (Talbot, 2014; Turan et al., 2017). Based on past experiences, they may come to anticipate

more people treating them in the same way. Similar to others who suffer from unfair prejudice and discrimination, HIV-positive individuals who internalize their stigmatization are likely to suffer from lower self-esteem, avoidance coping, and self-blame (Turan et al., 2017; Talbot, 2014). Stigma sufferers experience adverse impacts on their health, making them more susceptible to disease and more serious manifestations of symptoms from both HIV and other illnesses (Talbot, 2014). HIV-stigmatized patients, similar to many other discriminated individuals, may sometimes begin to "think they deserve their devalued status", lowering their self-esteem and willingness to resist the stigmatization (Talbot, 2014, p. 2).

#### 3.1.2 Social Dominance Orientation (SDO) Theory.

High levels of hostility and prejudice may be related to Sidanius and Pratto's (1999) *Social Dominance Orientation* (SDO) theory, which claims that "those higher in SDO believe that society should be hierarchically structured" and discriminate against people who are physically different (racism and/or ableism), as well as those who suffer from socially unaccepted diseases such as HIV/AIDS (Talbot, 2014, p. 18). Some scholars believe that high SDO individuals lack agreeableness and tender-mindedness, as well as believe "groups must compete with each other for resources" (Talbot, 2014, p. 19). Thus, high SDO individuals are often prejudiced against HIV-positive patients, whom they look down upon as social inferiors, and perhaps feel HIV-related treatments are costing the health care system too much, leaving fewer medical resources for themselves. Higher social class individuals and groups consider themselves social superiors to homosexuals, sex trade workers, and injection drug addicts who are among the highest at-risk groups for this disease (Talbot, 2014).

Many people both in the medical profession and in society in general feared contracting HIV/AIDS from someone already infected with the virus (Talbot, 2014). This combination of fear of HIV-infection and prejudice against "already devalued outgroups" such as homosexuals was a "perfect storm" for the spread of HIV-related stigma (Talbot, 2014, p. 21-22). Such widespread discriminatory attitudes are common in many societies and the resultant enacted stigma can cause much mental and emotional pain to innocent individuals who have enough issues to deal with. Fortunately, hostility towards HIV-positive individuals does declines with increased knowledge and public education on the disease, but only if people are willing to be open-minded about the realities of HIV.

## **3.1.3** Social Identity (SI) Theory.

According to Tajfel and Turner's (1979) *Social Identity Theory*, an individual's self-concept is closely tied to the social group he/she belongs to (Talbot, 2014). Being stigmatized for contracting the HIV virus often results in loss of membership to that group, especially if other members are fearful of contracting the disease and are misinformed about how HIV is transmitted. Talbot (2014) states, "emotional reactions of fear or disgust elicit avoidance and confrontation most often follows feelings of anger" or revulsion (p. 16). If higher ranking members of their social group harbour or exhibit repugnant feelings toward a group member diagnosed with HIV, then social identify theory suggests the likelihood of other members drawing back from socially supporting their ill member increases significantly (Talbot, 2014). The social stigma of HIV can lead to loss of social status and the resulting isolation can contribute to serious emotional responses and mental health issues, such as depression, shame, self-blame, low self-worth, embarrassment, and "poor medication and [medical or psychosocial supports] visit adherence" (Turan et al., 2017, p. 2). For instance, Orza and colleagues (2015)

found that 78 percent of HIV-positive women surveyed reported experiencing rejection as a result of HIV-related stigma. The same study found that fear of rejection is a significant barrier to disclosing their HIV-status, even to close friends and family members. For PLHA, fear of rejection or discrimination can lead to social isolation and loneliness (Kalichman et al., 2017). Any single or combination of such resulting issues can seriously impact the patient's sense of hope and will to fight back against his/her illness. For PLHA, the social stigma of HIV can have a significant impact on their mental and physical health-related quality of life (Cesnales, Thyer & Albright, 2017). Losing their social identity or status as a result of HIV-stigma can lead to depression and other mental health impacts.

#### 3.1.4 Intergroup Emotions Theory (IET).

Similar to SI theory, Mackie, Devos and Smith's (1993) *Intergroup Emotions Theory* (IET) posits the idea that "different types of prejudice and distinct behavioral reactions... are determined by emotional reactions toward other groups" (Talbot, 2014, p. 16). In the case of HIV-related stigma, IET would manifest itself as emotional reactions of fear and/or disgust towards people infected with the HIV virus (Talbot, 2014). These group emotional responses would then lead to avoidance, discrimination, and rejection of HIV-related stigmatized outgroups, including HIV-positive gay men (Rueda et al., 2016; Rendina et al., 2017). Such strong group emotions are found to be related to group identification, so that shared anger towards or fear of HIV-diagnosed outgroup(s) has been positively related to identification with an ingroup" (Talbot, 2014, p. 16).

Finding support in their shared emotional response to an HIV-related outgroup may be a "positive" outcome for the high SI group, but it can result in stronger, more organized or

widespread HIV-stigmatization of outgroup(s) members. Even worse is when the ingroup consists of "health-care providers and health professionals" who become the "source of the stigma affecting people living with HIV" (UNAIDS, 2014, p.6). When this happens, the health care ingroup members may begin neglecting patients, providing lower quality care and treatment to HIV-positive patients, denying proper medical care and breaching HIV-positive patient's confidentiality (UNAIDS, 2014; Chambers et al. 2015). All these HIV-stigma-based acts of discrimination can, and do, have deleterious effects on their HIV-positive patients' health and welfare, causing them to suffer physical, mental, emotional and psychological harm. The fact that sometimes acts of HIV-stigma are perpetrated by medical "professionals" is reprehensible.

## 3.1.5 Syndemic Theory.

Singer's (1995) *Syndemic Theory* (ST) postulates that socio-structural determinants of health, such as poverty and unstable housing, along with comorbidities such as substance abuse and psychiatric disorders, are responsible for adverse physical and mental health outcomes among disadvantaged populations (Tsuyuki et al., 2017). When combined with being HIV-positive, patients from disadvantaged groups tend to exhibit heightened anxiety and stress due to their unstable financial and housing status. Compared to individuals who are more stable financially, low-income HIV patients must deal with the anxiety associated with trying to afford all the added financial burdens associated with being HIV-positive, including the possibility of losing their jobs once their employers or co-workers find out (Lynch, 2016). Unemployed individuals must similarly deal with the potential barrier to employment that their HIV-diagnoses pose to their chances of getting a new job (Serrano, 2015).

### 3.2 Depression and Heightened Anxiety

Not surprisingly, among those suffering from HIV-related stigma, depression is one of the most commonly diagnosed mental health issues (Turan et al., 2017; Braithwaite et al., 2016; Ironson, Fitch and Stuetzle, 2017). In fact, Ironson and colleagues (2017) found "the prevalence of clinically significant depressive symptoms is three times higher in people living with HIV than in the general population (p. 749). Orza and colleagues' (2015) mixed quantitative/qualitative study on women with HIV found that 82 percent of 1173 female mental health survey respondents self-reported that they had experienced depression and depressive symptoms, most frequently post-HIV diagnosis. Depression can often result from HIV stigmatization or as a mental health reaction to the news that one's life is now put on hold as a result of this new and unexpected "stressful or traumatic life event (STLE)" (O'Donnell et al., 2016, p. 322). Depression is also widely identified as a contributing factor to worsening a patients' long-term survival with HIV by hastening disease progression (Rendina et al., 2017; Moskowitz et al., 2014). Unlike a cancer diagnosis, which usually results in an outpouring of emotional support from people who love or care about the patient, learning that a person has been infected with HIV often has a deleterious opposite effect (Talbot, 2014). Whereas cancer is a non-communicable disease, allowing friends and family members to have close, even intimate contact with the cancer patient, HIV is known to be highly infectious and communicable through infected body fluids (Panigrahi, 2017).

Due to lack of true knowledge about how HIV is transmitted, many people continue to believe that simple skin-to-skin contact, hugging, hand shaking, kissing, or using the same bathroom as someone who is HIV-positive is enough to become infected (Panigrahi, 2017). The uninformed, for instance, many mistakenly believe that being sneezed on or coughed on by the

patient means contracting the disease, when a bloodless sneeze or cough is generally harmless to people with functioning immune systems (Panigrahi, 2017). These misconceptions about HIV transmission cause many people to subconsciously decide to be fearful, stay away or cut off all physical contact with their friends or family members who are HIV-positive. Depression from social isolation is the mental health impact of such self-preservation behaviours, which is particularly harmful since their fears are based on incorrect information.

The truth is that treating an HIV-positive patient or visiting someone diagnosed with HIV is perfectly safe as long as certain precautions and protocols are followed to avoid becoming contaminated with body fluids (Panigrahi, 2017). However, the innate fear felt by countless people, including health care trainees and professionals, at even the thought of a tiny risk of becoming infected is psychologically difficult to overcome, resulting in harm to the patient's mental health status and health outcome (Wagner et al., 2014; Talbot 2014). One evolutionary explanation behind HIV-related stigmatization is that people's innate fear of death heightens their self-preservation instinct, causing them to fear disease transmission and stigmatize those with infectious diseases such as HIV/AIDS (Talbot, 2014). Unfortunately, the HIV-stigma resulting from these individuals' fear of death or other excuses can contribute to the HIV-patient's depression and other mental health challenges.

Rueda and colleagues' (2016) literature study of 64 studies on this topic uncovered significant associations between HIV-related stigma and HIV-positive patients suffering from higher rates of depression. Their depression can be directly tied to their feelings of shame and emotional distress over their HIV-positive diagnosis. The research group's meta-analysis of 22 articles revealed that studies controlling for potential confounders by using multivariate analysis "found that people living with HIV who experienced HIV-related stigma were at a greater risk of

higher depressive symptoms" (Rueda et al., 2016, p. 7). As with individuals suffering from depression due to other causes, the most serious impact of this mental health outcome is feelings of utter hopelessness and thoughts of (leading to) suicide among depressed HIV-positive patients. As long as they can maintain some sense of hope, they can fight off depression and suicidal thoughts, which is why many studies found social support and other coping mechanisms to be significantly important from a mental health/anti-depression perspective (Rueda et al., 2016).

Rueda et al.'s (2016) meta-analysis of six studies reporting univariate results found a "moderate correlation between HIV-related stigma and heightened anxiety" (p. 7). In two studies which controlled for confounders, researchers found patients experiencing HIV-related stigma experienced anxiety 1.09 times more frequently compared to patients who were relatively free of HIV stigma. Heightened anxiety from being stigmatized or simply from living with HIV/AIDS is a mental health issue that can adversely affect the health and well-being of HIV-positive patients.

#### 3.3 Increased Life Stress

Even among those who have not suffered from depression, being diagnosed as being HIV-positive is almost guaranteed to raise one's life stress level significantly. Each patient must learn to cope with the multitude of life stresses they face, both HIV-related and non-HIV-related. In most cases, just receiving the life-altering news that they have tested positive for HIV results in a high stress life event (Moskowitz et al., 2014). Whereas pre-diagnosis, their major life stressors were likely similar to what others in their society worried about, their post-diagnosis life stressors mostly involved their HIV-positive status (Orza et al., 2015). Post-diagnosis, many individuals became extremely stressed over how to tell their family and friends, new constraints to their sexual behavior, the need to deal with a complex health care system, and to come to

terms with being diagnosed/identified as a person living with HIV (Moskowitz et al., 2014; Orza et al., 2015). Much of this post-diagnoses life stress can be attributed to fear of being stigmatized by family, friends, their community or even their health-care providers once news of their HIV-positive status becomes known (Chambers et al., 2015). For instance, many women felt lonely because they were too stressed and fearful of being stigmatized to "fully confide in friends" after being diagnosed with HIV (Orza et al., 2015, p. 5). Some individuals associated their HIV-diagnoses with causing them to experience a form of Post-Traumatic-Stress Disorder (PTSD), resulting in nightmares and loss of sleep (Orza et al., 2015).

Their post-diagnosis period was often associated with increased levels of depression and anxiety as they must deal with questions of disclosure, as well as with their future plans being dramatically altered (Moskowitz et al., 2014). For example, when one woman told her *Planned Parenthood* doctor that she was now HIV positive, she was told that she "could never have children. That [she] might infect them and [she] would be [a] 'horrible woman' to do so" (Orza et al., 2015, p. 6). She was also encouraged to be sterilized as a medical precaution against becoming pregnant (Orza et al., 2015). Being HIV-positive does not automatically mean her own children will be born HIV-positive, yet her doctor caused her unnecessary pain and suffering by his callous words and dispassionate, almost cruel sterilization suggestion (Loutfy et al., 2016). In this case, being involved in the *Planned Parenthood* program should have suggested to her doctor that having children was a high priority in the woman's life. HIV-positive women are able to have HIV-negative children, although advising her about the risks involved in starting her own family required a gentler, more understanding approach in order to minimize the new stress and anguish her diagnosis has caused (Loutfy et al., 2016).

Another very common HIV-related life stressor is the sudden loss of employment many people suffer when their employers learn they are HIV-positive (UNAIDS 2014, p.6). In one study by Bengtson and colleagues (2015), out of 115 participants with a median age of 44 years, mostly males (69%), and mostly African-American, non-Hispanic (63%), only 24% were employed when the research was being conducted. With so few research participants employed, the mean monthly income was less than \$1,500 US, or under \$17,000 US annually (Bengston et al. 2015). According to the US Census Bureau (2016), male workers in 2015 earned an average of \$41,615 and female workers averaged \$30,246; therefore, HIV-positive individuals earned well below the national average and most would be classified as living below the poverty line. O'Donnell and colleagues (2016) cited research that revealed financial problems and unemployment are the two most common "stressful or traumatic life events" [STLEs] experienced by HIV-infected individuals (p. 3). The researchers found that depression suffered by HIV-positive workers can increase the incidence of work-related STLEs, such as risk of getting fired from their jobs, which would result in increased financial stressors (O'Donnell et al., 2016).

Revealing their HIV-diagnosis to their employers also leaves the worker vulnerable to HIV-related stigma and the risk of their employer looking for ways to "legally" fire, discharge or limit where they can work within the company (such as not being allowed to work in "jobs involving food handling") without being accused of discrimination (Gordon, 2015, p. 224; UNAIDS, 2014). Serrano (2015) found that many HIV-positive workers consider their diagnosis to be a significant barrier to employment. Applicants fear not being considered for a new job once they disclose their HIV-positive status if the hiring manager holds negative attitudes towards HIV-diagnosed people or is guilty of other prejudices (Talbot, 2014). Not hiring job

applicants who disclose their HIV-positive status is one way for potential employers to avoid dealing with any issues that may happen as a result of HIV-stigma among the existing staff or management, but that is little consolation for the unemployed HIV-diagnosed individual.

Among employed HIV-positive workers, even if their employers are understanding or perhaps fear the financial and legal repercussions of unlawfully firing someone without cause, social identity theory posits that disclosure of their HIV-diagnosis may result in enacted stigma from their co-workers who, as a group, fear getting infected with the HIV virus (Serrano, 2015,; Talbot, 2014). According to UNAIDS (2014), people living with HIV experience extremely high unemployment rates which are three times higher than their national averages. Among the reasons reported by the unemployed HIV-positive individuals are "stigma, discrimination, restrictive policies and practices and ill health" (UNAIDS, 2014, p. 5).

In Canada, citizens diagnosed with HIV/AIDS are treated by the public health care system. Unfortunately, being poor and HIV-positive in America can greatly increase life stress levels simply because health care is generally a for-profit industry south of the border. The extremely high costs associated with anti-retroviral HIV treatments and other medical procedures or treatments are beyond the financial resources of anyone living at or below the poverty line. Modern anti-retroviral therapy, if initiated immediately upon HIV diagnosis, has the potential to optimize health outcomes and suppress the virus (Moskowitz et al., 2014). Yet, the knowledge that this life-saving, life-extending therapy exists but is financially out of reach for individuals without health care insurance or the money to cover the costs privately can be devastating to patients who simply cannot afford these therapies.

In terms of accessing vital health and social services, many of the women surveyed by Orza and colleagues (2015) highlighted the need, in the United States, to "increase access to mental health services for low income women, preferably without payment" (p.7). In the United States, many of these services are offered by for-profit organizations so individuals without the proper medical or health care coverage/insurance may be limited in their choices or access to such services. Providing people with access to the services they require will not only eliminate some of their life stressors, but may prolong their lives, allow them to deal with their mental health issues, and improve their quality of life. Unfortunately, some studies have found that the greatest impact of anticipated stigma is the reduction in patients' adherence to taking their anti-HIV medications and patients missing scheduled health care appointments (Kalichman et al., 2017). Therefore, not only is greater access to psycho-social and medical services required, but it is important to also deal with PLHA's anticipated stigma from the people providing such essential services.

### 3.4 HIV-Associated Neurocognitive Disorder (HAND)

HIV-associated cognitive impairment is a significant health concern among individuals aging with HIV/AIDS, which increases their fear of being stigmatized as they grow older. Their concern is not surprising considering as many as 50 percent of all PLH/PLHA will eventually be impacted by HIV-associated neurocognitive disorder (HAND) (Vance, Cody, and Batey, 2015, p. 553; Grant et al., 2014). HAND is a neurological disorder which results in cognitive impairment among PLH/PLHA (Grant et al., 2014). In contrast to HAND's 50% rate among PLH, the estimated dementia rate among Canadians and Americans in general is only two percent (Alzheimer's Association, 2018; Alzheimer's Society of Canada, 2018). Researchers found that PLH aged 50–69 may actually have the cognitive function of someone aged 70-89

who is HIV-negative (Cohen, Seider, and Navia, 2015). Moreover, epidemiological trends reveal "HIV-infected adults over age 55 comprise the fastest-growing age group in the HIV-positive population, and advanced age at the time of seroconversion increases the risk for neurocognitive impairment" (Cohen et al., 2015, p. 1). For PLHA, especially among the growing number of older adults, aging with this added risk of neurocognitive impairment is a source of great anxiety and fear (Vance *et al.* 2015).

According to Eaton, Craig and Wallace (2017), "HAND is classified in three forms: asymptomatic neurocognitive impairment (ANI), mild neurocognitive disorder (MND), and HIV-associated dementia (HAD)" (p. 734). Both MND and HAD are known to result in significant disruption to PLHA daily activities, including regular adherence to taking their anti-HIV medications, paying attention and completing normal, everyday tasks such as washing dishes or cooking (Grant et al., 2014). Fortunately, thanks to medical breakthroughs such as the highly effective combination antiretroviral therapy (cART), there has been a shift away from HAD (the most serious form of HAND) and towards the less serious MND and ANI forms of HAND (Grant et al., 2014). Early detection of ANI in PLH is considered essential because treatment options can then be employed to delay a person's cognitive declines. Strictly following their cART treatment's schedule is essential to preventing the onset or progression of HAND (Grant et al., 2014).

Since PLH suffering from HAND is characterized by slower or reduced mental cognition, memory loss and reduced ability to concentrate, many aging PLH live with increased anxiety and fear of HIV-stigma (Eaton et al., 2017). This form of HIV-associated dementia can also result in poor medication adherence and social isolation, as the PLH forget to take their pills and their dementia make them fear being discriminated against or stigmatized for becoming a "burden" to

their family and friends. Eaton and colleagues' (2017) HIV and social work-specific research concluded that social workers should have the resources and training to help mitigate these HAND-related mental health issues. The key is to immediately connect newly HIV-diagnosed people with the medical services they need to begin their cART or other modern anti-HIV treatments, since starting their treatment can mitigate the onset or severity of HAND (Eaton et al., 2017).

According to Grant et al. (2014), comorbidities such as HIV-stigma-related depression, alcohol or substance addiction, and post-traumatic stress disorder (PTSD) have been found to exacerbate HAND's impact on people aging with. Further, a study comparing HAND prevalence rates between employed/actively volunteering PLH versus unemployed PLH found fewer working/volunteering PLH suffered from HAND (Eaton et al., 2017). Overall, studies have found that generalized psychosocial interventions for PLH have proven to be reasonably effective in "normalizing experiences, improving health and well-being, and advocating for social change" (Eaton et al., 2017, p. 735). However, not much is yet known regarding the role of social work when it comes to delivering psychosocial support to HAND-affected older PLH.

#### 3.5 Increased High-Risk Behaviours

Dealing with the stress and stigma of being HIV-positive can cause some individuals to increase the frequency and level of high-risk behaviours, such as having unprotected sex, smoking or drinking excessively. Whereas smoking and depression were more common among HIV-infected individuals among Braithwaite and colleagues' (2016) research participants, harmful alcohol consumption was more prevalent among non-infected individuals (p. 570). Kaplan and Ironson (2017) also found that cumulative depression and increased stress among

HIV-positive patients was associated with alcohol dependence. They conclude that interventions should aim at reducing stress and increasing focus on coping strategies to reduce depression and related high risk behaviours (Kaplan & Ironson, 2017).

Tsuyuki and colleagues (2017) found that syndemic comorbidities such as depression, drug/alcohol use disorders, or violence, are "important predictors of HIV transmission risk and HIV treatment outcomes" (p. 2271). In other words, someone who is HIV-positive and suffers from drug or alcohol use disorder is far more likely to engage in high-risk behavior such as unprotected sexual activities without telling their partners compared to individuals without such syndemic comorbidities. Their research, which involved an analytic sample size of 481 men and women, also identified a gender disparity with anxiety and depression contributing more "to the syndemic in heterosexual men compared to heterosexual women" (Tsuyuki et al., 2017, p. 2270). Conversely, heterosexual women are more affected by substance use disorder compared to heterosexual men.

Moskowitz and colleagues (2014) found that even years after diagnosis, the stress and depression arising from the stigma of living with HIV/AIDS is associated with high risk activities such as "increased sexual risk behavior" (p. 86). Other research findings suggest that internalized HIV-related stigma, in combination with sexual minority stigma, are most associated with increased HIV-transmission-related high risk behaviours, including not disclosing HIV status to sexual partners and having condomless sex (Rendina et al., 2017). Overwhelming empirical support suggests individuals are more comfortable disclosing their serostatus if they know their confidant's serostatus, and most likely to disclose their HIV-positive serostatus if the confidant is already known to be diagnosed as HIV-positive (Talbot, 2014). Studies have found that HIV infection rates are disproportionately high among Gay and Bisexual Men [GBM].

Rendina and colleagues (2017) suggest that internalized HIV-related stigma and sexual minority stress theory help explain why GBM are more prone to high risk behaviours. Sexual minority stress theory refers to GBM living with devalued social status which compounds any general life stress they may be experiencing (Rendina et al., 2017). When GBM with minority stress live in "stigmatizing social structures that perpetuate stigma and discrimination" across various aspects of normal life, such as a person's workplace, school, hospital, family or neighbourhood, the probability of resorting to high risk sexual behaviours increases (Rendina et al. 2017, p.148). Their study involving 376 GBM participants, of whom 169 (44.9%) were confirmed HIVpositive, found that HIV-related stress had a stronger effect on mental health and risky sexual behavior than did the study participants' sexual minority stress. Internalized HIV-stigma was found to be independently associated with the participants' mental health, sexual behavior, and emotional dysregulation (Rendina et al., 2017). Unfortunately, when patients feel stigmatized by their health care providers, such as nurses or doctors, they may internalize that stigma which might later manifest itself as destructive, high-risk behaviours. Among patients whose health care workers stigmatize them due to their HIV-diagnoses, one high risk behavior an HIVpositive patient may choose is to begin missing treatment sessions or even quitting their anti-HIV treatment regimen altogether (Wagner et al., 2014). Wagner and colleagues (2014) stated that "perceived stigma from health care providers decreases the likelihood people living with HIV will access health care" (p. 2397). For the cause of social justice, social workers working with HIV-positive individuals should support their clients by seeking ways to reduce various forms of HIV-related stigma and mental health challenges they experience in their lives from medical health professionals and others in order to improve their quality of life and ensure they fulfill their medical treatment programs.

### 3. Gaps in the Literature

One gap in the literature is with regards to the appointment of case managers for each client diagnosed with HIV. Although improving the quality of life for PLHA is a "long-recognized goal of case management services", there is a gap in the literature regarding the true effects on the Health-Related Quality of Life [HRQoL] for PLHA of case management services (Cesnales et al., 2017, p. 199). Past studies have been unable to definitively prove whether it is access to a case manager that improves the PLHA's HRQoL or whether having a case manager act as a mediator between the different variables which contributes to higher HRQoL (Cesnales et al., 2017). Future research studies can seek to fill in this gap in the literature.

Another gap in the literature is the lack of HAND research on other groups, such as women, heterosexuals, and visible minorities, since the main HAND study analyzed in this paper was conducted on primarily on male (88%), gay (79%), and Caucasian (97%) participants (Eaton *et al.* 2014). Ethnicity and/or race could play a significant role in not only HAND-related issues but other mental health issues discussed in this paper. Perhaps a more diverse subject group would reveal different mental health concerns and issues, as well as test the effects of other Social Determinants of Health [SDOH]. Future research on this topic could involve studying HAND-related concerns of visible minorities or a more culturally diverse group of participants.

Finally, a limitation of this report is the lack of gender equality in the research papers analyzed in this literature review on HIV-related stigma and other mental health issues. Most of the studies included in this review were conducted on men or mostly male participants. One key exception is Orza and colleagues' (2015) research study, which was the largest study conducted on women and their HIV-stigma concerns, according to the authors. Few other reports analyzed

focused on studying the concerns of HIV-positive women-only or involved primarily female study participants.

#### 4. Implications

#### 5.1 Social Work in HIV

Wagner and colleagues' (2014) research support the work of an internationally jointly developed initiative by major HIV/AIDS stakeholder organizations, including UNAIDS, that "speaks to the need to assess stigma globally among people living with HIV in order to decrease their experience of stigma and increase quality of life" (p. 2398). Moskowitz and colleagues (2014) also advocates for the "need for effective, creative, client-centered interventions" for HIV-diagnosed individuals (p.85). Among those providing care and support for HIV-positive patients, social service agents can have the most significant impact on the daily lives and psychosocial well-being of individuals suffering from various forms of HIV-related stigma and mental health issues. As Lynch (2016) explained, social workers have the "important person-inenvironment perspective, grounded in social justice that is uniquely social work in nature, is often lacking in many... medical colleagues" (p.427). A 2014 study conducted on social workers by Rodriguez and McDowell found the participating social workers were, in general, comfortable working with PLWHA (people living with HIV/AIDS) clients and did not possess strong stigma levels towards their clients. This finding supports infusing the profession's central "values of social justice and human dignity into all HIV care and treatment" and is why social workers play a key role in supporting the many needs of HIV-positive clients who are suffering from various forms of HIV-related mental health issues (Lynch, 2016, p.429).

### 5.2 Ongoing Training and Upgrading

It is also true that continued training and monitoring is necessary to ensure that social workers remain focused on seeking social justice and solutions for their clients, without stigmatizing them for their HIV-positive status. In Canada and the United States, practicing social workers are the largest providers of essential social services and they "need to remain informed and social work education should adequately prepare new professionals" (Pelts et al., 2014, p. 131). Since a large percentage of HIV-positive cases involve members of the lesbian, bisexual, gay, transgender and queer [LBGTQ] community, social workers must receive sufficient specialized training in dealing with this group of sexual minorities. However, when program directors and key faculty members from 157 Council on Social Work Education (CSWE) accredited social services programs in the US were surveyed on how well the curricula of their respective programs address LGBT issues, the survey results revealed some unfavorable findings. According to research by Pelts and colleagues (2014), 53 percent of surveyed CSWE program directors and 41 percent of CSWE faculty members admitted their programs only did "slightly well or not well at all" when it came to training "students to provide competent services to people who identify as LGBT" (p. 132). To adequately educate and train future social workers who must deal with LGBTQ2S individuals who are HIV-positive, these CSWE programs must be improved by adding more curricula content to focus on LGBTQ2S-related issues and concerns, as well as the HIV dimension. Pelt and colleagues' (2014) literature search also revealed a lack of published information related to the needs of people diagnosed with HIV/AIDS or preventative measures.

Lichenstien and DeCoster (2013) stressed how the primary objective of HIV/AIDS courses in sociology should focus on stigma reduction, partly because "attitudes toward HIV

typically reflect moral judgments rather than fears of contagion" (p. 1). In many cases, people (including medical personnel and even some social workers) harbor beliefs that most PLHA are "classified as deviant in the public imagination" (Lichenstein and DeCoster, 2013, p. 1). Challenging people's strongly held prejudices in the classroom is essential so that students (i.e. future social workers) do not continue to hold onto such beliefs and end up causing harm to their future clients through acts of HIV-related stigma. Future social workers must learn about the harm HIV-related stigma causes and how it can become a barrier for PLHA when it comes to seek HIV prevention or treatment or other psycho-social services (Lichenstein and DeCoster, 2013). Refresher courses can provide the same training and information to working social workers to ensure they do not practice HIV-stigma to their clients.

### 5.2.1 Resilience Training: Learning to Survive Personal Challenges/Traumas.

Social workers can teach their clients proven resilience strategies in order for them to cope with personal challenges or life traumas, and improve their own HRQoL. Resilience training may help mediate the relationship between life stress and various facets of HRQoL (Fang et al., 2014). Emlet and colleagues (2017) learned from their interviews of many older HIV survivors was that many had faced significant personal challenges in their lives before gaining the life-saving resilience they needed to face life with HIV. Some of those traumas may be directly associated to their HIV-diagnosis and treatments, such as experiencing HIV-related stigma from their health care providers (Wagner et al., 2014). Other reported challenges included suicide attempts, facing their "death sentence", mental illness, sexual assault, and loss of relationships with peers, colleagues, and loved ones post-diagnosis (Emlet et al., 2017).

Similarly, Earnshaw and colleagues (2016) found many survivors experienced traumatic events such as death of loved ones and HIV-related discrimination. Having survived these traumatic

events in their lives, interviewed long-term survivors credited their development of various personal self-care strategies for their improved health resilience as they learned to age well with HIV.

Among the most commonly shared self-care behaviours identified in these studies which social workers can educate their clients are developing routines such as eating healthier, reducing stress, giving up potentially harmful vices, and exercising regularly yet ensuring they have sufficient rest to not over-tax their immunity-compromised bodies (Emlet et al., 2017). They went to therapy, developed stronger friendships and became involved within a positive social circle, and pursued hobbies and interests they were passionate about. Many patients also gave up overconsumption of alcohol and smoking as they tried to live without these vices (Braithwaite et al. 2016, p. 5-6). For such individuals, learning they are HIV-positive forced them to re-evaluate their lives and try to adopt healthier, more positive life habits, such as eating healthier and avoiding harmful behaviours such as smoking and alcoholism (Solomon et al., 2017). Cesnales and colleagues (2017) report that studies of HIV-diagnosed individuals who use tobacco, alcohol or drugs report "lower levels of HRQoL" (p. 199). Based on these research findings, social workers can advise their clients on which habits and behaviours will benefit their physical and mental health and aid in their long-term survival with this disease (Solomon et al., 2017). Instead of living as if they will live forever (or at least a full, healthy lifespan), their diagnosis is a reality check that life is both precious and fragile. Giving up bad habits is simply acting on this new realization, an attitude and behavioural change which people who are not HIV-positive could also learn from. For instance, rather than self-medicating their mental health issues with high volumes of alcohol or other mood-altering substances, HIV-positive clients can add light

exercise such as walks around their neighbourhood to their daily routine as part of a healthy lifestyle and hopefully their outlook on life will improve as a side benefit (Solomon et al., 2017).

#### 5.3 Holistic Strategies for Reducing Impact of HIV-Related Stigma on Mental Health

Even in North America, where equality and human rights are protected by law, the issue of HIV-related stigma experienced by patients from their health care providers continues to be widely reported (Stringer et al., 2016). Many research papers on HIV-related stigma and other mental health issues mention how study participants self-reported to be suffering from loneliness, despair, and feelings of helplessness when dealing with their disease and a sometimes uncaring health care system (Wagner et al., 2014; Stringer et al., 2016; Orza et al., 2015; Chambers et al., 2015). Medical treatments alone are far less effective if the client's "critical underlying psychosocial realities" are not properly understood and addressed, whether it is poverty, HIV-related stigma (either from medical professionals or others), unemployment or inadequate housing (Lynch, 2016, p. 427).

In the largest survey of women living with HIV, participants of Orza and colleagues' (2015) study recommended "psychological support and counseling, peer support, challenging stigma and promoting human rights" as ways to really alleviate some of the mental health issues experienced by HIV-positive people (p. 7). Rather than dealing with the various agencies and organizations alone, PLHA need to be aided by people specially trained to give them the counseling, support, and timely interventions to deal with all the bureaucracies associated with accessing HIV-related medical and psycho-social services. Therefore, a more holistic approach, including the assignment of HIV case managers/social workers to advocate for their clients and

seek ways to improve their clients' overall quality of life, provides social workers with the best chance of success at overcoming these HIV-related challenges (Lynch, 2016; Orza et al., 2015).

# 5.3.1 HIV Case Management.

Both Orza and colleagues (2015) and Cesnales and colleagues' (2017) findings include recommending the "coordination of services through assessment, planning, linking, monitoring, and advocacy" (p.199). By having a single HIV case manager in charge of coordinating the different psycho-social services and HIV-related programs for each individual client, there is far less confusion, less replication of similar services, and higher overall efficiency (Cesnales et al., 2017). HIV case managers are better able to reduce potential barriers to care and to help clients access social services in order to provide "PLHA with continuity of care" essential for reducing the stress and worry of their clients (Cesnales et al. 2017, p. 199). In general, having one person who knows "everything" about an HIV-diagnosed person's case, such as who they have seen, what treatments they have received, and what programs they are enrolled in, simply makes good sense.

In a study conducted in Miami, Florida and Atlanta, Georgia, HIV-positive inpatients were interviewed to determine the effectiveness of having an assigned case manager (Kenya et al., 2015,). The researchers investigated whether being assigned a case manager was associated with positive outcomes and behaviors by their clients with regard to "unprotected sex, HIV care, use of antiretroviral medications, and referral to case management at time of diagnosis" (Kenya et al. 2015, p.95). When patients' outcomes were compared between those with case managers and other PLHA without their own case manager, participants with case managers did significantly better in many respects. For instance, these PLHA with case managers were more

likely to consistently take their HIV medications and obtain HIV medical/psycho-social care, as well as being far less likely to engage in high risk behavior such as unprotected sex (Kenya et al., 2014). This study found PLHA with current assigned case managers are more likely to exercise positive HIV health-seeking behaviors and less likely to risk the possibility of disease-transmission via unprotected sex. These qualitative findings suggest having assigned case managers can lead to improved clinical results and better overall outcomes for their PLHA clients (Kenya et al., 2015).

### **5.3.2** Stronger Advocating for HIV-Diagnosed Clients.

Since real and perceived HIV-stigma from health care workers has become a barrier to HIV-positive patients accessing medical treatments and continuing the "very real demands of complex HIV treatment regimens", social workers must be trained to stop even the appearance or acts of HIV-stigma by medical professionals (Lynch 2016, p.428). Although doctors and other medical professionals are generally held in high respect by the general public, their professional status does not preclude them from harboring prejudicial beliefs or stigmatizing their HIV-positive patients (Wagner et al. 2017). Although in the minority, studies have found in both medical students and practicing health care workers that HIV-stigma is held towards patients with HIV/AIDS (Chambers et al. 2015). Some of the HIV-stigma can be linked to other prejudices (such as homophobia) and the moral judgment of health care workers who feel their patients' lifestyles and actions brought this disease upon them (Lichenstein & DeCoster, 2013). However, Chambers et al. (2015) found that some actions and attitudes are "attributed expressions of nervousness among health care staff to fears of transmission" (Chambers et al. 2015, p.6).

Social workers should be able to improve their clients' quality of life by advocating for them to show support and letting PLHA know others care. As a first step, they can advocate for their clients by investigating any claims of HIV-stigmatization such as "denial of care, confidentiality breaches, negative attitudes, and humiliating practices by health care workers" (Chambers et al. 2015, p.849). Generating dialogue between patients and their health care workers can increase empathy and understanding, which is one of the keys to reducing HIVstigmatization by medical professionals and others (Chambers et al. 2015). Hopefully, by opening up a dialogue with the medical personnel their clients report are stigmatizing them, the social worker can both advocate for their clients and mediate an acceptable resolution to the issue. If face-to-face discussions fail, the social worker can bring their client's complaints about HIV-related stigma from their health care workers to the authorities to seek a solution because clearly, "eradicating stigma in the health care system is essential to provide fair and just care" (Wagner et al. 2014, p.2397). In the interest of social justice and PWHA's human rights, social workers must use all their available resources to stop HIV-stigma enacted by medical professionals as required by their Social Workers Code of Conduct (SWCoC). Reducing HIVrelated stigmatization has a positive side effect of promoting healthier attitudes and better mental health among HIV-positive patients. Reduced HIV-stigma promotes positive affect, with its associated health benefits, among those who once suffered from discrimination due to their HIVdiagnoses.

At the same time, more work must be done to ensure social workers (and other medical professionals) working with HIV-positive individuals do their jobs to the fullest of their abilities regardless of any personal reservations, in particular homophobic beliefs and belief in social superiority (Lichenstein & DeCoster 2014; Wagner et al. 2017). After conducting their own

literature review of the Lesbian, Gay, Bisexual, Transexual, and Queer [LGBTQ] population and social workers, Pelt *et al.* (2014) found, over the last quarter century of social work, some social workers have been inconsistent in their service to this sexual minority group with regards to the obligation "to championship the rights of the most vulnerable" members of society (p.137). Since so many HIV-positive individuals are members of the LGBTQ2S community, advocating for HIV patients' rights often overlaps with advocating for this sexual minority group. A social worker who is homophobic or is unable to work around their homophobia should not be dealing with this group of clients. Without well informed education to deal with these "moral judgment" concerns, such a social worker may become a detriment, rather than the strong advocate PLHA need when seeking out appropriate social and medical services and programs (Lichenstein & DeCoster 2014, p.1-2).

#### 5.3.3 Improving Health-Related Quality of Life (HRQoL).

Social workers can also help reduce the impact of HIV-related stigma from health care providers (and other people) by supporting their clients' needs in order to improve their clients' overall quality of life. Health-related quality of life (HRQoL) is a highly complex multi-dimensional concept which includes both physical and psychological/mental health (Cesnales et al. 2017). Studies have found strong evidence that "life stress is inversely associated with both physical and mental HRQoL among HIV-infected persons" (Fang et al. 2014, p.2). Furthermore, HRQoL is related to a person's sense of well-being, including their social well-being, and varies widely when dealing with vulnerable populations, such as sexual minorities, immigrants with HIV, and other outsider groups (Cesnales et al. 2017). Reducing stigma and resulting symptoms such as depression and anxiety are ways to improve the mental health-related quality of life for PLHA.

The difficult-to-answer question of how to improve quality of life may be answered by seeking out long-term survivors to find out their "secrets" for aging successfully with HIV. Emlet, Harris, Brennan, Furlotte and Pierpaoli's (2017) Canadian qualitative HIV study sought to answer the question of what HIV survivors identify as contributing factors (personal characteristics and resources) for successful aging with HIV among older Canadians. Their study involved semi-structured, in-depth, face-to-face interviews conducted between February and May of 2013 on 30 long-term HIV survivors in Ontario. These HIV-positive individuals were recruited through AIDS clinics, service organizations, and service providers in Toronto and Hamilton. Study participants self-perceived as "aging well with HIV" ranged in age from 50-73 years (M=58+/-6.1) with 66.7% male, 66.7% White, 13% Black Canadians. Furthermore, 60% self-identified as LGBT, averaged 18 years since first being diagnosed as HIV positive, and 56% were diagnosed before active antiretroviral therapy (ART) became available (p.755). The same researchers conclude having to deal with HIV-stigma to be a significant impediment to successful aging among HIV-positive individuals. Social workers and counselors should, therefore, teach their clients various resilience strategies in order to help improve their quality of life and to achieve successful aging with HIV (Emlet et al. 2017).

#### 5.3.4 Test All HIV-diagnosed Individuals for HAND.

With an approximated 50 percent of all PLH being affected by HAND, especially among older adults, compared to only two percent of the general population of Canada and America testing positive for dementia, it is imperative to increase the level of HAND testing (Vance et al. 2015; Grant et al. 2014). For those PLH who worry about being stigmatized for their HIV-diagnosis, developing HAND and losing their mental cognition functions has been found to increase their stress, worries, and have other mental health impacts (Eaton et al. 2017). Early

detection of HAND can mean the difference between being able to effectively treat and mitigate its effects on the HIV-positive patient and having that person advance from asymptomatic neurocognitive impairment (ANI) to the far more serious HIV-associated dementia (HAD) state (Eaton et al. 2017).

If detected early, doctors can initiate treatments to hopefully arrest the progression of HAND in the tested PLH patient. Cognitive Remediation Therapy (CRT) has so far been found to be the most promising psycho-social intervention for the treatment of PLH affected by HAND (Eaton et al. 2017). CRT involves having middle-aged and older adult HAND-affected PLH work regularly on computer-based exercises and has proven to decrease the subjects' HAND-related stress and anxiety (Eaton et al. 2017). Whether it is CRT or other treatment option, testing HIV-positive people soon after they are diagnosed and as they grow older is the key to minimizing HAND.

However, simply pushing to have their PLH clients tested for HAND is not enough. The qualitative data indicates PLH fear cognitive decline (and the stigma that can result from developing HIV-associated dementia), as well as fear being alone or becoming an unbearable burden to their family, friends, and health care staff (Eaton et al. 2017). Social workers working with HIV positive individuals can also address their clients' HAND-related concerns, helping to alleviate their anxiety about their future, find solutions to their future medication adherence challenges, and prevent their fears about HIV-stigma and HAND-related stigma from leading them to choose social isolation (Eaton et al. 2017). Social workers can counsel their PLH clients and ensure they gain access to psycho-social services and supports to address these fears. By advocating for more frequent HAND testing and addressing their HAND-related fears, social

workers can improve their PLH clients' HRQoL and deal more effectively with their mental health issues and concerns.

## **5.3.5** Reduce HIV-Self Indentifying as Positive Affect Intervention.

Social workers can help their clients to learn to accept the disease as a smaller component of their identity and life, and teach them ways to increase positive affect to reduce their HIV-related stress levels (Wagner et al., 2014). Batchelder, Carrico, Acree, Hecht and Moskowitz (2017) found that evoking positive affect among HIV-positive individuals is "associated with beneficial health behaviors" (p. 1). Not self-identifying as "only" HIV-positive was found to be a key strategy for improving one's quality of life and successful aging with this disease (Emlet et al., 2017).

The women living with HIV in Orza et al.'s (2015) study recommend HIV counselors work with their clients to develop "an understanding of the need to build a life based on wellbeing and acceptance not over focusing on problems of the past" (p.7). PLHA who receive counseling for their mental health issues, such as obsessing too much on their HIV-diagnosis, have showed improved HRQoL after being counseled, whereas PLHA who did not receive mental health counseling showed little or no HRQoL improvement (Cesnales et al. 2017). Social workers and mental health counselors can teach their clients to look beyond their disease and focus on other aspects of their lives, such as their families, communities, or hobbies.

A person can avoid self-identifying as only HIV-Positve by staying positive and developing certain skills, such as exercising altruistic behaviours towards others such as committing small acts of kindness to strangers (Moskowitz et al., 2014, p. 87). Interventions to increase positive affect are especially critical during the months immediately after being

diagnosed HIV-positive since that is when patients will feel "high levels of stress, distress, and depression" (Moskowitz et al., 2014, p. 96). Thinking about others has the side effect of building up one's self-confidence by reestablishing one's identity as a positive influence and contributing member of society. Through the help of HIV/mental health counselors, instead of wallowing in self-pity, HIV-positive patients can look beyond their own health issues or past feelings of being stigmatized and discover ways they can be of service to someone else (Orza et al., 2015, p. 7). It may be as easy as communicating through emails, chats, texts, or Skype with seniors who are even less able to get out and meet people. Earnshaw and colleagues (2016) found that many PLHA chose to fight back against HIV-related stigma through activism. HIV activists in this HIV-stigma activism study reported "greater engagement in active coping with discrimination, and greater meaning in life than non-activists" (p. 717). Finding new purpose or being able to help others can be an effective intervention for increasing positive affect among HIV-positive clients. Social workers can explain how intentionally focusing on helping other people teaches the clients that they are still capable of being a positive influence on others even in their darkest, most difficult times in their own lives (Earnshaw et al., 2016, p. 722). By avoiding the pitfalls of overly self-identifying as HIV-positive, individuals may be able to work on developing other aspects of their lives/identities, have a healthier mental health outlook, and increase their positive affect.

#### 5. Conclusion

For individuals living with HIV/AIDS, the long-term toll on their physical health is well-documented. However, adverse impacts on their mental health are not as widely publicized, yet can be even more challenging for infected individuals to deal with. In North America, if HAART

or other treatments are started early enough, most of those "death sentences" have been commuted into a "largely manageable chronic disease." This literature review seeks to answer the research question "What is the current state of knowledge regarding the serious mental health issues suffered by adult patients diagnosed with and learning to live with HIV/AIDS and how social workers can help meet their needs and challenges?" Key findings include the widespread suffering of People Living with HIV/AIDS [PLHA] caused by HIV-related stigma (enacted, internalized and anticipated), by medical professionals and others. Depression, increased lifestress, HIV-Associated Neurocognitive Disorder [HAND], heightened anxiety and increased high risk behavior (such as engaging in unprotected sex) are the main mental health issues and challenges resulting from HIV-related stigma. Past researches recommends taking a comprehensive holistic approach to reduce HIV-related stigma. Effective measures for HIV-stigma reduction includes, but is not limited to, additional anti-stigma training for future and current social and health care workers, HAND-testing, individual HIV-case management and stronger advocating for HIV-positive clients.

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