The Impacts of Care Giving on The Wellbeing of Caregivers of People Living With HIV/AIDS

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Abstract

Research has shown that caregivers are confronted with a number of stressors such as burnout, compassion fatigue, and post-traumatic stress disorder as a result of being in direct or close contact with the people suffering from chronic diseases such as HIV/AIDS. However, relevant and professional training, and effective self-care strategies could prevent such stressors. Using the "Individual Interviews with Formal Caregivers" dataset, this study looked at the experiences of seventeen caregivers who provided care to stigmatized and low income people of living with HIV/AIDS. The study sought to understand how the well-being of caregivers was impacted by providing care to stigmatized and low income people living with HIV/AIDS in Manitoba and Saskatchewan. Also, it examined how formal caregivers perceived their relationship with people living with HIV/AIDS at their care.

The findings suggested that caregivers were confronted with and experienced stressors such as burnout, compassion fatigue, and secondary traumatic stress due to having direct and close relationships with people living with HIV/AIDS in their care. Medical caregivers treating HIV/AIDS patients perceived these as formal professional relationships; however, most caregivers working in community support, community outreach, and education sectors understood their caregiving relationships with people living with HIV/AIDS as that of supporter and helper. There was not much research on how caregivers in HIV/AIDS sector perceived their relationships with people living with HIV in their care, so further research is needed to explore the nature of the relationship between the caregiver and care recipients. Finally, this study enriched the existing research on this topic by providing an insight on how caregivers in HIV sector perceive their relationships with individuals living with HIV/ AIDS in their care.

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CHAPTER ONE

Introduction

The life span of people living with HIV/AIDS has gradually prolonged due to improved medical therapy and the common use of prophylactic treatments (Ettner &Weissman, 1994; Land & Hudson, 2002). The existence and utilization of home-based care in relation to HIV/AIDS treatment has increased and its role has expanded as people living with HIV/AIDS in need of chronic care rely more on long term care of home and community programs. Challenges have arisen in the provision of formal caregiving versus informal caregiving as some nursing homes were reluctant to accept people living with HIV/AIDS and hospice programs were less suitable for the needs of young HIV-positive individuals (Ettner &Weissman, 1994; Uphold & Mkanta, 2005).

According to the Public Health Agency of Canada (2010), the number of individuals living with or at risk of HIV/AIDS has increased in Canada. In the province of Saskatchewan, the number of reported HIV/AIDS cases increased drastically between 2003 and 2007 from 124 to 195 cases; while in the province of Manitoba, the number HIV/AIDS cases increased from 75 to 105 cases between 2007 and 2009 (Mignone, Pindera, Davis, Migliardi, Harvey, Bending & McNabb, 2011).Statistics also indicated that a significant number of new HIV/AIDS infections have occurred within marginalized sectors of the population, particularly among low-income Aboriginal Peoples, newcomer refugees, Black Canadians and injection drug users (Dickson-Swift, James, Kippen, & Liamputtong, 2009).

Mignone and colleagues found in their 2011 community-based study, that "the virus disproportionately affected poor and stigmatized communities, placing great emotional and material strains on those living with HIV/AIDS and the people who cared for them"(p.5) and

noted that a large portion of low-income people affected with HIV/AIDS and living in stigmatized communities, usually relied on peers living in similarly precarious conditions and on formal caregivers for support rather than family members or close friends. Such findings presented a challenge in the delivery of home-based services for marginalized populations that no longer possessed support networks, which have been severed through a history of substance abuse, unstable relationships, and could no longer rely on family or friends for caregiving.

Research showed that the provision of formal and/or informal care for people living with HIV/AIDS was challenging. Even though such caregiving was limited, they appeared to be perceived as central to the lives of those individuals in care (Mignone et al., 2011). The majority of individuals with chronic conditions needed help and support in many areas like health care, mental health, aging, and developmental disabilities (Cummings & Kropf, 2009). In the mental health sector, for example, people with psychiatric conditions usually depended on combined care and support from family, friends, programs, and interventions to improve and maintain their functioning and well-being although access to all kinds of services or to the ones that were most appropriate for their condition was not always available(Cummings & Kropf, 2009).

In the healthcare sector, research suggested that professional workers who provided care for people with chronic diseases and survivors of traumatic experiences were exposed to different forms of stressors. The stress expressed itself in various ways such as burnout, compassion fatigue and vicarious traumatization (Sabo, 2006), and although the caregivers might also have experienced compassion satisfaction. Vicarious traumatization, secondary traumatic stress, compassion fatigue, and burnout were interlinked; therefore, they were used interchangeably to refer to similar conditions. Nonetheless, recent research has been conducted to differentiate between these forms of stress (Craig & Sprang, 2009; Alkema, Linton, & Davies, 2008).

Stress is defined as a dynamic interaction between person and environment where certain situations or environmental tasks are seen as exceeding the person's skills and abilities, taxing, or jeopardizing his or her well-being (Lazarus & Folkman, 1984). In the long run, intense levels of stress might result in burnout (O'Halloran &Linton, 2000; Payne, 2001). Burnout has been defined as "a syndrome composed of emotional exhaustion, depersonalization, and reduction of personal accomplishments" (Jenaro, Flores & Arias, 2007, p. 80). Burnout could also lead to negative attitudes about work, negative self-concept, and a loss of caring about work-related issues (Keidel, 2002).

Burnout is associated with the feelings of hopelessness, inability to carry work effectively, and the feeling that work-related efforts do not make any differences in the lives of those being served. Thus, it can be stated that burnout is a response to work-related stress (Alkema et al., 2008). Also, burnout is expressed as a process in which the professional caregiver's behavior and attitude are affected in negative ways due to the job strain arising out of the sense of powerlessness, frustration, and inability to achieve work goals. As a result of such negative impacts, a disconnection comes into play between the expectation of professional caregivers' role performance and the structure of the organizations to support the professional role (Alkema et al., 2008; Sobo, 2006).

It is essential to differentiate compassion fatigue from burnout as there is some overlap between them. Burnout is associated with a gradual wearing down of the professional caregiver over a long period of time whereas compassion fatigue is the outcome of an acute attack. Burnout increases the likelihood of developing compassion fatigue. Compassion fatigue is the outcome of a 'natural' consequence of providing care for individuals who are suffering rather a response to the work environment (Alkema et al., 2008; Sabo, 2006). Alkema et al. (2008) argued that burnout typically has a slow onset which is the result of prolonged work-related

matters whereas compassion fatigue is a result of "specific secondary exposure to traumatic events"(p.104) also known as vicarious trauma. Health care practitioners can experience compassion fatigue after they listen to stories of traumatic suffering and death of a loved one from people in their care. Compassion fatigue's symptoms can have a fast onset and can be related to one particular event or continuing exposure to many traumatic stories (Alkema et al., 2008; Stamm, 2002). Burnout can be experienced by workers in any professional field, but compassion fatigue is specific to those practitioners who are in the helping professions and listening to clients' stories of traumatic events (Keidel, 2002).

Compassion fatigue is a recent term which is being used widely in replacement of secondary traumatic stress because it provides a better framework than the pathologized secondary traumatic stress disorder (Alkema, et al., 2008; Sabo, 2006). Compassion fatigue communicates a more 'user-friendly' framework than the secondary traumatic stress disorder (Alkema, et al., 2008; Sabo, 2006). Compassion fatigue is assumed to be a mixture of burnout and secondary traumatization that comes into play after the delivery of care and bringing healthcare professionals into a close contact with suffering. Compassion fatigue and post-traumatic stress disorder (PTSD) are different from one another. In compassion fatigue an individual is exposed to the traumatized or suffering person while PTSD is associated with the traumatic event itself (Alkema, et al., 2008; Sabo, 2006).

Epidemiological research studies have indicated that those caregivers who were placed in the frontlines of treating trauma were at high risk of developing compassion fatigue. Shah, Garland, and Katz (2007) discovered that 100% (N=76) of humanitarian aid employees reported compassion fatigue as a result of their work. Another study conducted in 2002 in Australia found that 27% of community mental health case managers experienced intense levels of stress due to serving traumatized people (Meldrum, King, & Spooner, 2002). A number of factors have been

identified that influence the risk of developing compassion fatigue such as female gender

(Sprang et al., 2007), length of time providing sexual abuse treatment (Cunningham, 2003), age

(Ghahramanlou & Brodbeck, 2000), increased exposure to traumatized clients (Brady et

al.,1999), clinician's own maltreatment history (Nelson-Gardell & Harris, 2003), and

occupational stress (Badger, Royse & Craig, 2008).

On the other hand, display of compassion in the long-run does not necessarily lead to

negative emotional states of burnout and compassion fatigue, and can result in a sense of

compassion satisfaction. Compassion satisfaction refers to the enjoyment that one achieves from

being able to do his or her job effectively. According to Raphael, Singh, Brady, Bury, and

Lambert (1983) compassion satisfaction enhances a sense of personal growth for caregivers as a

result of their work. In general, compassion satisfaction is perceived to be related to seeing

affected people and clients change in a positive way, and recognizing a positive impact of the

health care practitioners on these people (Radley & Figley, 2007). A number of factors and

actions such as being optimistic, having a positive effect, utilizing several social resources,

leading a balanced life, and maintaining good health can enhance compassion satisfaction

(Radley & Figley, 2007).

More recent research has discovered that specialized trauma training of therapists

significantly enhanced compassion satisfaction and decreased compassion fatigue and burnout

(Sprang et al., 2007). Personal therapy and supervision in conjunction with therapeutic work had

a positive relationship with compassion satisfaction. Linley and Joseph (2007) found that female

therapists reported more positive psychological outcomes due to receiving personal therapy and

supervision in relation to their therapeutic work. The results of a study conducted by Craig and

Sprang (2010) revealed that using evidence-based practices have significant impact on levels of

compassion fatigue, burnout, and compassion satisfaction. In the absence of evidence-based

practices, age and years of experience proved to be powerful predictors: Amidst younger professionals there were higher levels of burnout; and more experienced workers displayed higher levels of compassion fatigue. The use of evidence-based practices predicted statistically significant increases in compassion satisfaction, and decreases in burnout and compassion fatigue (Craig & Sprang, 2010).

Using the "Individual Interviews with Formal Caregivers" dataset, this study looked at the experiences of seventeen caregivers who provided care to stigmatized and low income people of living with HIV/AIDS. The study sought to understand how the well-being of caregivers was impacted by providing care to stigmatized and low income people living with HIV/AIDS in Manitoba and Saskatchewan. Also, it examined how formal caregivers perceived their relationship with people living with HIV/AIDS at their care.

The chapter that follows provides a review of the literature in relation to burnout, compassion fatigue, the role of health care providers, and formal and informal caregivers. Chapter three explains in detail the methodology used in the study. The findings are presented in chapter four, followed by a discussion of the findings in chapter five.

CHAPTER TWO

Review of the Literature

In the review of the literature regarding issues of providing care and/ or treatment to individuals living with HIV/AIDS, specific topics relevant to this study: compassion fatigue, burnout and compassion satisfaction; factors that influence the development of compassion fatigue and the management of burnout and compassion fatigue; the role of health care providers and organizational changes that may affect caregivers perception, especially in the context of differences between formal and informal caregivers. This review led to the research questions that are presented at the end of this chapter.

Prevalence of Compassion Fatigue/Burnout and Compassion Satisfaction

Health care practitioners such as nurses and caregivers are exposed to higher levels of compassion fatigue and burnout due to experiencing intense levels of stress at their workplace. According to Palfine (2008), socio-demographic factors do not contribute to the progress of burnout and compassion fatigue but the severity of patients' conditions and degree of permanent stressful circumstances in the intensive care units. The forerunners to a professional burnout include employee workload, imbalance between family and career, sickness absence, compassion fatigue and loss of confidence (Alkema et al., 2008).

Alkema et al. (2008) tried to identify the relationship between self-care, compassion fatigue, compassion satisfaction, and burnout. Compassion fatigue is negatively correlated to all aspects of self-care suggesting that as compassion fatigue and burnout increase, the number of self-care activities by health care practitioners decrease. The study found a negative correlation between compassion satisfaction and burnout; and compassion satisfaction and compassion

fatigue; and a strong positive correlation between compassion fatigue and burnout (Alkema et al., 2008). Compassion satisfaction was positively correlated with the emotional, spiritual, and balance subscales of the Self Care Assessment Worksheet (SCAW) but not with the psychological, physical, and workplace subscales. The researchers posited that engaging in a number of self-care strategies may prevent burnout and compassion fatigue. Also, only higher levels of compassion satisfaction can be attained by emotional/spiritual self-care, personal, and professional balance (Alkema, et al., 2008).

Alkemaet al. (2008) also looked at the relationship between several demographic variables (age, gender, length of tenure in the field) and levels of compassion fatigue, burnout, compassion satisfaction, and self-care. Health care practitioners with more months of service in the profession seemed to be taking care of themselves in all areas of self-care to a greater extent than those with less experience. Their findings suggested that those who took care of themselves in various areas of self-care are less likely to leave the profession early because of burnout or compassion fatigue. Those who started the profession later in life are equally susceptible to burnout if they do not take care of themselves in various self-care areas (Alkema et al., 2008).

Factors That Influence Development of Compassion Fatigue

Smith (2007) tackled one of the core issues that social workers are confronted within different sectors of social work when they are in direct and challenging practices. For example, the majority of social workers in clinical treatment/support settings experience compassion fatigue while caring for traumatized clients. The trauma could be the result of various disasters such as war combat, HIV/AIDS, substance abuse, and a history of abuse or trauma as a child and adult or both. Most of the social workers join the workforce as a result of change of career in their mid-thirties and often come with no relevant and professional training. On the other hand,

massive turnover in the social work field lies on the strain of empathic work with poor

compensations which in return opens doors for untrained newcomer workers who are highly

exposed to the risk of developing compassion fatigue, burnout, secondary trauma, and post-

traumatic stress disorder (Smith, 2007).

Smith (2007) presented a metaphor of a "sifter" as a way to conceptualize the process by

which compassion fatigue emerges for social workers who work with people living with

HIV/AIDS and other traumatized populations. He argued that clinical social workers must sift

through the complex and heart-rending stories of trauma presented by their clients to prevent and

manage compassion fatigue. The quantity of traumatic narratives from the clients can overwhelm

the self-care strategies of the practitioners which make the "sifter" incapable of working

effectively.

Craig and Sprang (2010) presented a wide range of literature confirming a number of

variables that influence the risk of developing compassion fatigue. These variables include:

female gender, increased exposure to traumatized clients, age, occupational stress, length of time

providing sexual abuse treatment, and clinician's own abuse history. However, there was some

conflicting evidence on the clinician's own abuse history as some research has suggested that the

clinician's own abuse history does not contribute to cause or increase compassion fatigue. Craig

and Sprang (2010) found evidence of the fact that a personal history of trauma exposure

increases the likelihood of compassion fatigue.

Management of Burnout/Compassion Fatigue

Sprang and Craig (2010) reviewed a number of studies which disclosed some factors that

work as barriers in the development of compassion fatigue. These factors are: access to clinical

supervision, perceived coping ability, training for new and inexperienced clinicians, and the amount of clinicians experience, emotional separation, social support, and self-care strategies.

Caregivers are in charge of people in various settings where they are expected to respond to many needs and demands. At the same time, many caregivers might be experiencing continued grief and loss (Carmack, 1997). The review of several studies clearly described the burden of caregiving, "loss saturation" and "chronic trauma" which all can cause caregivers and nurses to feel emotionally overwhelmed. Moreover, with the expected deaths from AIDS and other major diseases, caregivers are more likely to confront the sense of loss and grief. Therefore, caregivers must learn to balance their engagement and detachment with people in their care. Retaining a balance between engagement and detachment can assist caregivers to be present for others while still meeting their own needs. It is hard to apply and understand balance; therefore teaching adaptive coping strategies is difficult (Carmack, 1997).

As Carmack stated, "The longer and the more intense a caregiver's involvement is, the more important it becomes to balance engagement with detachment"(Carmack, 1997, p. 142).This involves focusing on the here and now, recognizing one's limits, and making an attempt not to over-control outcomes. Balance can be manageable, controllable, and sustainable. When people successfully balance engagement and detachment they know what they can and cannot control or change. Moreover, they are sensitive to their own emotional needs; thus, they decide on their level of engagement based on what they know that they can handle at a specific time. Finally, people who have learned how to balance engagement and detachment well recognize the importance of self-care. When caregivers engage in self-care strategies (physical exercise, proper nutrition, and adequate sleep) they are more likely to continue to provide compassionate care without being overwhelmed (Carmack, 1997).

On the contrary, Smith (2007) argued that engaging in self-care activities (eating well, exercising regularly, sleeping well, and occasionally meditation) are not enough to avoid experiencing compassion fatigue. At a non-profit AIDS service organization, Smith was a supervisor of both clinical and operational activities. As a supervisor, Smith regularly taught, advocated and encouraged self-care strategies. Despite engaging in various self-care methods, it did not prevent him from experiencing compassion fatigue. Eventually, Smith left clinical work and moved to HIV/AIDS prevention research projects. In his study, Smith highlighted the need for additional research in the area of prevention of compassion fatigue. He also warned that if adequate self-care methods are not put in place at an organizational level or if a providers' "sifters" mechanisms break down due to the severity and continuity of the trauma shared with practitioners, a compassion fatigue epidemic could ensue among care providers (Smith, 2007).

White (2006) concluded that management of compassion fatigue is not only a concern of the individual clinical health care practitioners, but also of the managers of such organizations. White advised that managers need to be aware of the costs associated with negative impacts of caregiving and suggested steps to mitigate these negative effects on caregivers affected by providing care for people of chronic diseases. White (2006) pointed out to certain intervention strategies that managers could implement to assist their staff struggling with the negative effects of caregiving. These strategies included educating staff about the effects of compassion fatigue, secondary trauma and vicarious traumatization and identifying them as an organizational top priority. Furthermore, organizational awareness and prevention campaigns could help employees perform better since caregivers would not be struggling by themselves to cope with the physical, emotional, and psychological impact of providing care. After all, managers are responsible to ensure that organizational policy development is aligned with current knowledge of prevention programs. Managers could consider using measurement tools such as the "Professional Quality

of Life Scale" to measure the impact provision of care is having on the staff. The Professional

Quality of Life Scale is a self-delivered tool that can measure compassion satisfaction, burnout,

and secondary trauma and compassion fatigue. In addition, educational workshops could serve as

a forum to increase knowledge, skills, and self-awareness of the effects of providing care. These

workshops could also help to decrease feelings of isolation and teach coping skills to the staff.

The coping skills training should include how to de-stress from the events of the day and

emphasize the need to find a balance between work and home. Creating a culture of care within

the workplace could also provide additional support to staff and increase the trust between

managers and staff which could result in increased employee satisfaction and staff more willing

to voluntarily engage in behaviors that go beyond their formal job requirements (White, 2006).

Fahy (2007) reflected on two manual models that could be used for mental health and

substance abuse care providers to help them reduce their struggle with compassion fatigue and

trauma. These models are *Seeking Safety* and *Trauma Recovery and Empowerment Model* to help

counselors achieve a more healthy interaction with their clients. The *Seeking Safety* module

offers twenty five topics with handouts and support for treatment providers and clients' own self-

help. The *Trauma Recovery and Empowerment Model* offersa similar thirty-three session group

intervention that utilizes cognitive education and skill building along with self-soothing and

development of healthy supports and coping. There are other interventions tools that assist

counselors to reach a more naturally healthy stand with their clients. These tools are *Harm*

Reduction, *Motivational Interviewing* and *Narrative Therapy*. However, more studies need to be

done to determine their effects on counselors. Fahy (2007) concluded that substance abuse

counselors have neglected their need for adequate supervision and visioning around workforce

issues.

Role of Health Care Providers

For people with chronic diseases, it is challenging to maintain regular engagement, retention, and adherence in clinical care. Many people living with HIV/AIDs come from hard-to-reach populations that have historically distrusted health authorities; consequently, the act of disclosing one's HIV status to a care provider maybe perceived as a risk and aggravates anxiety (Mallinson, Rajabiun, & Coleman, 2007). The research revealed an association between "patient-provider relationships" and "patient satisfaction with care"; "disparities in quality of care", and "adherence to HIV medications". Mallinsonand et al. (2007) examined the process by which persons living with HIV/AIDS engage in the primary HIV medical care for treatment after knowing of their HIV status. One of the main purposes of this study was to find out, from the perspective of people living with HIV/AIDS, what specific provider behaviors sway their engagement in care. The results of this study revealed that the provider has a crucial role as either a facilitator or as barrier in the process of engagement and retention of people living with HIV/AIDS in HIV primary medical care. Similar to participants in other studies among marginalized HIV-positive individuals, the participants in this study expressed a preference for health providers who they could trust. The participants also wanted healthcare providers who demonstrated respect, caring, efficient communication skills and expertise. Furthermore, the participants sought health care providers who went "above and beyond" their role to develop relationships, advocate for clients, and treat them as unique human beings. These findings support the importance of providing training to health care clinicians on emotional intelligence.

Emotional intelligence is an emerging concept within the field of medical education which is defined as a type of social intelligence that involves the ability to monitor one's own and others' emotions, to discriminate among them, and to use the information to guide one's thinking and actions (Mallinson et al., 2007). Medical studies have found that increased

emotional intelligence could be a valuable asset for improving patient care and supported

recommendations for training programs that enhance clinician skills related to emotional

intelligence. On the other hand, if care and services do not adhere to the cultural context of

people living with HIV/AIDS, or if health information is incomprehensible or not meaningful to

people' lives, efforts to engage them can be useless. Therefore, providers who polish their skills

in communication maybe better equipped for assessing how to best partner with HIV/AIDS

people to optimize the HIV care experience. According to Carmack (1997) promoting mutually

beneficial encounters between people of HIV/AIDS and their providers is crucial to effective

care and to reduce providers' frustrations.

Organizational Changes

The mortality rate of people living with HIV/AIDS has declined significantly due to the

new and improved medical therapy. New drugs such as Zidovudline and prophylactic treatments

have lowered the risk of more insidious opportunistic infections (Ettner &Weissman, 1994). The

fact that HIV/AIDS has essentially become a chronic disease has had a tremendous impact on

service organizations. The number of people accessing AIDS service organizations has widely

grown since people need services for a longer time period. The emphasis on medical treatment

has moved from treating people with AIDS to treating people living with HIV. Another outcome

of this new HIV/AIDS environment is that less help is coming from donors since the primary

motivation of a donor is the death of a person due to AIDS. To cope with this new HIV/AIDS

environment, some AIDS service organizations are not only adapting existing services but are

also creating new ones. Many agencies are focusing on clients returning to the workplace

through back-to work programs and resume-writing programs. With the shift in the HIV/AIDS

epidemic, AIDS organizations have had to stay flexible to meet the emerging needs (Gallagher, 1997).

Formal and Informal Caregivers

In a broad sense, caregivers can be categorized as formal caregivers and informal caregivers. A formal caregiver is an individual who possesses professional caregiving skills obtained through academic education and training in a particular field of caregiving. A formal caregiver is compensated through an employer when care is provided to a person in care. Formal caregivers can also be volunteers of organizations that provide services to people living with HIV/AIDS (Mignone et al, 2011). An informal caregiver is an individual who voluntarily provides assistance to a person in need of care. Informal caregivers may or may not have professional caregiving skills. Informal caregivers are often family members, friends, community individuals, and are likely to come from the same ethnic and cultural groups as that of the people in their care. Informal caregivers are not employed officially to be compensated by an employer or by the individual in care. The caregiver is considered informal because the relationship between the caregiver and the person in care is not established or regulated by any organization or employer (Mignone et al, 2011).

Informal care is broad and diverse and could address different areas of needs such as activities of daily living like housework chores (meal preparation and cleaning); personal care including dressing, toileting and mobility needs; administrative tasks such as bill payment and money management; and socializing (e.g., comforting and emotional support).In formal caregiving settings, all of these tasks are not performed by one formal caregiver but in coordination with others and while providing care for more than one person. As Van. Den, Berg,

Brouwer, and Koopmanschap (2004) have explained that the primary caregiver may coordinate the care provided by other caregivers and also they may provide most of the informal care.

However, nursing homes are reluctant to take HIV-positive individuals and hospice programs may be unsuitable for the needs of young people (Ettner &Weissman, 1994). Thus, HIV-positive people have mainly relied on home and community-based long-term care. Researchers believe that people infected with HIV utilize care services differently from other sick populations and they are appropriate candidates for formal home care services (Ettner &Weissman, 1994). People living with HIV/AIDS of middle and low income heavily rely on informal caregivers as formal caregiving is unaffordable.

In general, women (e.g., mothers, sisters, aunts, girlfriends) are seen more often than men to be the primary caregivers of people living with HIV. As Mignone et al.suggests, "Differences in the lifestyle of low income persons from stigmatized communities may affect the availability of informal care when confronted with HIV/AIDS" (p.9). People may be unwilling to care for HIV-positive individuals due to the associated stigma with their condition which is a belief that they are personally responsible for their conditions (Mignone et al., 2011).

Research Questions

Through personal interviews with formal caregivers in HIV/AIDS sector, this study looked into the experiences of formal caregivers who provided care to stigmatized and low income people living with HIV/AIDS to discover whether the wellbeing of formal caregivers was affected by providing care to people living with HIV/AIDS. Also, there was an examination of how formal caregivers perceived their relationships with people living with HIV/AIDS in their care. The qualitative data which was previously collected from seventeen formal caregivers who

worked for five different AIDS service organizations was analyzed and to sought answers to the following research questions:

➢ How do caregivers perceive their relationships with stigmatized and low income of people living with HIV/AIDS?

➢ What are the problems and issues that caregivers face in relation to providing care for stigmatized and low income people affected by HIV/AIDS?

➢ What is the caregivers' perception of their own wellbeing in relation to the work they do, and in relation to being at-risk of burnout, compassion fatigue, and vicarious traumatization?

➢ What kinds of formal/professional boundaries do caregivers establish with their clients, what are the positive and negative aspects of these boundaries, and what challenges do these boundaries pose?

CHAPTER THREE

Research Methodology

The study analyzed data of a study conducted in 2009 entitled *Social Support, Informal Caregiving and HIV/AIDS: A Community-Based Study* that was done in partnership with the University of Manitoba, Nine Circles Community Health Centre (Winnipeg) and AIDS services organizations from Regina. The data was collected using two methods: 1) A variation of Photovoice with people living with HIV/AIDS; and 2) In-depth individual interviews with caregivers. The present study solely analyzed data from the interviews with the caregivers.

A research coordinator in Winnipeg and a research assistant in Regina were hired upon receiving Ethics Approval from the Health Research Ethics Board. Both of these staff members were experienced in working with AIDS services, research and sexuality education. Another research assistant was hired in Winnipeg for the recruitment process. The research team was large and was working from two different provinces (Manitoba and Saskatchewan) and relied on telephone, Skype, email, and standard post for communicating across the two research sites (Mignoneet al., 2011).

Individual Interviews with Caregivers

Recruitment of research participants began in December 2007. The research team conducted a series of interviews with caregivers in Winnipeg and Regina. An open email request was sent out within the partnering organizations seeking the participation of formal caregivers of people living with HIV/AIDS. Seventeen caregivers volunteered to be interviewed for the study. Since one member of the research team was program manager in one of the AIDS service organizations, the identities of the caregivers participating in the study were strictly protected.

The interviews were conducted by the research coordinator and by other members of the research team that had no employment connection with the organizations (Mignone et al., 2011).

A set of pre-determined questions were asked from the caregivers. Of the total participants, three were from Regina and fourteen from Winnipeg. All of them worked in five different AIDS service organizations. As well, seven worked in the area of community outreach and/or education (e.g., outreach workers); five were staff in the medical sector (e.g., doctors or nurses); three worked in community support sector (e.g., social workers); one was a board member of an AIDS service organization; and one was a front line receptionist in an AIDS service organization. These caregivers were all interviewed on an individual basis in a wide range of time: June, 2008; October, 2008; November, 2008; and January, 2009 (Mignone et al., 2011). The interviews were all audio-taped and were transcribed verbatim.

Working with Secondary Qualitative Data: As for this study, secondary qualitative data was used. All interviews were already transcribed and any identifiable information was removed from each transcript. After conducting a few meetings over Skype with Research Advisor, the researcher was approved to conduct research based on the existing dataset. To prevent post-hoc analysis, the research topic and the research questions were developed *a priori*, and later the researcher obtained access to the existing dataset (interviews of seventeen caregivers). The dataset was enriched to provide information on formal caregivers, informal caregivers, organizational boundaries, caregivers' well-being and so forth. However, it contained limited information on different types of stressors such as burnout, compassion fatigue, and post-traumatic stress disorder. Also, the dataset provided information on these stressors as a whole but it did not provide in-depth information separately on burnout, compassion fatigue, and posttraumatic stress disorder. Similarly, there was less information on stigma of HIV/AIDS in the formal caregiving settings within the dataset. Working with secondary qualitative data

proved to be extra challenging and thus, the researcher took extra precaution during thematic analysis to specifically focus on the research questions. Sifting through the narrative, the researcher extracted data in bulk and not just what was relevant to this study to minimize possible cognitive biases and illusory correlation. The researcher considered the limitations of analyzing existing data when developing findings, and acknowledged the secondary qualitative data studied was collected for a different study purpose.

Data Analysis

Thematic analysis is a commonly used method in qualitative research to identify, analyze, and report patterns (themes) within a data set. This method organizes and describes the data set in rich detail. Furthermore, it can go beyond descriptive detail and can be used to interpret various aspects of a research topic (Braun & Clarke, 2006). Thematic analysis illustrates which themes are important in the description of the phenomenon under the study. In the end, the results of a thematic analysis should emphasize the most recurrent and representative meanings encountered in the dataset (Braun & Clarke, 2006)

Thematic analysis is a very flexible method as it can be applied within different theoretical frameworks or can be used to do different things within them because it is not wed to any pre-existing theoretical structure (Braun & Clarke, 2006). For example, thematic analysis can be a realist or essentialist method that reports experiences, meanings and the reality of participants. Also, thematic analysis can be a constructionist method that examines the ways in which events, meanings, realities, experiences, and so on are the effects of a range of discourses operating within society. Moreover, it can be a "contextualist" method that sits between the two poles of essentialism and constructionism. Finally, thematic analysis can work both ways to reflect reality and also to untie or unravel the surface of reality (Braun & Clarke, 2006).

"A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set"(Braun & Clarke, 2006, p. 10). Given that a theme refers to a specific pattern of meaning found in the data, the notion of a theme must be examined very closely. The analysis will identify themes from the data using an inductive or "bottom up" method. An inductive approach means the themes identified are strongly linked to the data themselves. In this method, if the data has been collected specifically for the research the themes identified may bear little relationship to the specific question that was asked of the participants. They would also not be driven by the researcher's theoretical interest in the area or topic. Inductive analysis is therefore a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions. In this sense, this form of thematic analysis is data driven (Braun & Clarke, 2006).

Moreover, themes will be identified at a semantic level. "With a semantic approach, the themes are identified within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said or what has been written"(Braun & Clarke, 2006, p.13). Preferably, the analytic process contains a progression from description (during which the data is organized in order to show patterns in semantic content and summaries) to interpretation, where there is an attempt to theorize the significance of the patterns and their broader meanings and implications (Braun & Clarke, 2006; Patton, 1990) often in relation to previous literature.

Phases of Thematic Analysis

There were six phases involved in conducting thematic analysis: 1) Familiarizing yourself with data; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes; 5)

Defining and naming themes; and 6) Producing the report. These phases were similar to the

phases of other qualitative research but they were not essentially unique to thematic analysis

(Braun & Clarke, 2006) (See Figure 1).

As the data was pre-transcribed, there was no transcription of the data. The process

started with reading the entire data set a few times to become familiarized with the dataset.

Reading the dataset several times helped to recognize issues of potential interest in the dataset.

The entire analysis involved ongoing moving back and forth between the entire dataset. After

becoming familiarized with the data, some ideas were generated and noted down in order to help

with creating codes. Then coding process started and continued to be developed and defined

during the entire analysis. The codes were generated based on interesting, meaningful, and

relevant features of the data. The codes helped to capture basic elements within the dataset. Also,

coding helped to narrow down the dataset and to work with specific parts and pieces of the

dataset. After the entire dataset was coded, then codes were organized and alike codes were

merged together.

Collating, organizing and merging alike codes together helped to search for themes. In

order to look for and generate potential themes, codes were sorted and categorized in different

small groups. The code groups were reviewed several times after which the potential themes

emerged. Finally, a set of themes was developed and refined. The themes were reviewed and

some were merged. Reviewing and reading the collated extracts for each theme helped to

identify if they appeared to form a coherent pattern. The entire data set was then re-read to

ensure that themes worked in relation to the dataset. Re-reading helped to code any additional

data within themes that had been missed in earlier coding stages. By the end of this phase, a

number of different themes were formed to provide an overall perspective of the entire data set.

Finally, a thematic map was created to visualize each theme.

The fifth phase, defining and naming themes, started with having satisfactory thematic map of the dataset. Then each theme was defined and refined; and the data within each theme was analyzed. By defining and refining, it was meant to identify the core of each theme and was each theme was about as well as to determine what aspects of the data each theme captured. As part of the refinement, it was necessary to consider whether or not a theme contained any sub-themes. There were two sub-themes which formed one main theme. Finally, this phase ended by continuous refining the data within each theme to filter the specifics of each them and produce names for each theme.

After forming eight different themes, the final stage of data analysis began. Writing up the report contained data extracts to present the facts and evidence of the entire data set and as well as analytical interpretation of the themes. The report was based on eight different themes and the story behind them. In order to present a concise, coherent, logical, and non-repetitive report, it was necessary to use vivid examples from each theme. The extracts and examples were well embedded within the analytical narrative which provided an evidence based report.

Rigour of Analysis

Rigour in qualitative research involved in-depth planning, careful attention to the subject and topic under the study, and useful results (Fereday, and Muir-Cochrane, 2008; Horsfall, Byrne-Armstrong &Higgs, 2001).Braun and Clarke (2006) introduced six steps of analysis in order to conduct thematic analysis and maintain rigour within the analysis. In thematic analysis, consistency throughout the entire analysis process was the key to generate a thorough and transparent report.

Moreover, the six steps of analysis introduced by Braun and Clarke (2006): 1) Familiarizing yourself with your data; 2) Generating initial codes; 3) Searching for themes; 4)

Reviewing themes; 5) Defining and naming themes; and 6) Producing the report, were followed step-by-step in order to maintain the rigour and avoid inconsistency and any alteration or fabrications during the analysis process. Throughout the entire analysis process, consistency and transparency were essential to generate a thorough and evidenced based report. First step, the researcher read the data set a number of times to fully familiarize with the data and capture the important aspects of the data. Second step, the data extracts within the entire data set took place and then followed by coding the extracted data. Then the generated codes were labeled as "Initial Codes" and saved them as a Microsoft World document. The "Initial Codes" set of codes served as the main source of the codes for the entire data set based on which the "Final Codes" set of codes was generated. Throughout the entire analysis and coding process, any new set of codes generated in any stage of the analysis were added to the "Initial Codes" set of codes. The "Final Codes" set of codes was emerged from collating alike codes together. Both sets of these codes were kept separately in order to keep the process clear and make it easier to work between both sets of codes and not to miss on any important aspects of the data.

Third step, the researcher started reading the "Final Codes" set of codes to sort the different codes into possible themes. Rereading and collating different coded data extracts helped the researcher to categorize and create separate set of coded data extracts. The researcher created colorful tables (e.g. yellow, green, light blue, purple, orange and etc.) for each of these collated and categorized coded data extracts to help with organizing and distinguishing among possible emerging themes. The created tables and the collated coded data extract helped the researcher to create a thematic map. During this stage, it was important to think about the relationship between codes, between themes, and between different levels of themes such as main themes and sub-themes. Finally, by the end of this stage ten themes were generated and saved as "Initial Ten Themes" in Microsoft World Program.

The forth step started with having ten themes in hand to refine and finalize them. So, the researcher read these themes a few times to make sure that each theme was distinct and the collated extracts within each theme formed a coherent pattern. Then, the researcher compared and refined the themes where they noticed that there were two sets of themes that were not broad enough and the data within them could not support those themes. However, these two themes served as sub-themes and collapsed into two different existing themes where the data fitted together. Moreover, to test the validity of the individual themes in relation to the data set and whether the thematic map reflected accurately on research topic and provided responds to the research questions, the researcher re-read the entire data set and identified that themes and thematic map meaningfully evidenced the dataset as a whole. Also, re-reading the entire data set helped the researcher to code any additional data within each theme that had been missed in earlier coding stages. At the end of this stage, the researcher was able to come up with eight final themes and saved them as "Final Eight Themes" in Microsoft Word Program. As a whole, these themes fitted together and presented a story about the entire data set.

Fifth step, the researcher moved to the next stage of analysis where defining and naming of these themes took place. The researcher defined and further refined the themes. This involved identifying the real meaning of what each theme was about and determining what aspect of the data each theme captured. Then, the researcher went through the entire collated data extracts within each theme to organize the data into a sound and internally consistent account. At this stage, the researcher made sure that the content of the data extracts presented in each theme was not only paraphrased, but were identified to bring out what was interesting about them and why. In addition, the researcher took into consideration how the story in each theme would fit into the bigger overall story of the entire data set. In order to avoid overlap between themes, the researcher considered the themes themselves and each theme in relation to the others. Also, the

researcher analyzed each theme individually and wrote detailed analysis for each theme. For the refinement purposes, the researcher identified whether or not any themes contained a sub-theme. As this stage was almost at the end of it, the researcher needed to clearly define what their themes were and what they were not. In order to test this, the researcher checked if they could describe the content and scope of each theme in a couple of sentences. At last, each theme individually was given name. The names were chosen carefully to reflect meaningfully on each theme and to give the reader a sense of what each theme was about. The thematic map and fully worked-out eight themes were sent to the research advisor for review and feedback. The themes were reviewed by the advisor and agreed to proceed further with the research analysis.

The sixth step, started with having in hand a set of eight themes to use for final analysis and produce a report. The purpose behind producing this report was to tell the story of the entire data set in a way that it could convince the reader of the merit and validity of this analysis. Therefore, the researcher produced the report in a fair length of time in collaboration with the research committee. The researcher used existing research in the area of study, the evidence of the themes within the data, and relevant and specific examples from the data set.

Moreover, the researcher ensured that themes were actually analyzed not just described or paraphrased. Also, the research kept into consideration that the analytic claims and extracts were matching; and there was a balance between extracts and analytic narrative. Finally, during the entire analysis process, the researcher made sure that analysis were clearly explicated and there was a clear line between analyzing the data rather than summarizing the data.

CHAPTER FOUR

Findings

Using thematic analysis, eight themes were extracted from the entire dataset: 1) Caregivers' perceptions of their relationships with stigmatized people living with HIV; 2) Problems/issues linked with caregiving for stigmatized people living with HIV; 3) The risk to well-being of caregivers of people living with HIV; 4) Stressors related to caregiving in HIV/AIDS sector; 5) Implication of caregiving boundaries in formal settings for caregivers of people living with HIV; 6) Benefits of boundaries for caregivers of people living with HIV; 7) Obstacles and limitations to boundaries for caregivers of people living with HIV; and 8) Challenges that boundaries pose on caregivers of people living with HIV.

Caregivers' Perceptions of Their Relationships with Stigmatized People Living With HIV

In general, caregivers in the medical sector such as nurses and doctors who worked in different AIDS service organizations perceived their relationships with marginalized people living with HIV/AIDS that of a formal supporter and helper. These caregivers believed that they only built and maintained a formal relationship with people in their care. For these caregivers, this relationship was based on a responsibility that they needed to carry in formal settings only. For example, Bette, a nurse at one of the AIDS services, believed that she had a formal relationship with people in her care and she needed to support them and advocate for them when necessary. "...it is a responsibility of being a helper" (Bette).

>   Caregiving would be nurturing, guiding, being very respectful of where the
>   person's at but offering just another perspective like maybe with added supporter
>   just other ideas and helping the person access anything they might need like

health care or food. (Jackie)

Some of the community outreach workers and a volunteer caregiver perceived their relationship with stigmatized and low income people living with HIV/AIDS in their care as a limited and categorized relationship where they could not provide support to certain aspects of their lives. Molly, who volunteered at Nine Circles, believed that people living with HIV/AIDS need support in multiple areas such as spiritual, emotional, mental, and physical to improve their overall well-being, but caregivers could not offer such support due to the nature of their role and relationships with these people. Also, Molly stated, "… there is a natural support network. And sometimes I find that I can do more work in the natural support, than I can as the professional because I am limited, I'm boxed in, I'm categorized." In Molly's opinion, there were rules and policies in place at the organizational level which put limitations on the caregivers' movements and the extent that they could offer support to those people living with HIV in their care. "It has to do with rules, bureaucracy, policy and money… because if you're a caregiver you can be like a friend or family member… to be more formal coming from an agency I think perspective, then you may have the professional caregivers like the homecare workers." (Molly).

Likewise, in the community support sector, caregivers did not perceive their relationships with individuals living with HIV in their care as a formal/professional relationship but as a helper or supporter. "I want to put them at ease first and just try very hard to make that connection, so I don't throw any airs or any labels on myself. Just somebody that's there to listen to them and see what I can do for you" (Rita). This group of caregivers believed that their role was to offer meaningful support that could help these individuals to lessen or eliminate their fear through ongoing care and support.

Some outreach caregivers referred to having an informal and intimate relationship with the people in their care. To these caregivers, intimate and informal relationship meant that they

were well connected with the individuals in their care and it was beyond providing support and supervision. "I mean certainly people are aware that I have a job here, like I think they know that I have things to do um but because it is different than a nurse or it is different then, you know because I don't provide them with formal care…. Um caregiving seems intimate to me." (Maggie). These caregivers believed that because they were not providing support with medication or supervising them with anything, and having a "loose-line" kind of relationship, they perceived their relationships as more of a social supporter than a formal caregiver. "It has to me a very intimate connotation, just the word itself, as opposed to doing my job, which might include providing support, supervision or things like that..." (Maggie).

Similarly, some caregivers in the community support sector also perceived their relationships with marginalized people living with HIV/AIDS that they were providing care for as a formal and informal relationship. These caregivers acknowledged the fact that due to being employed by an organization they were labeled as "formal caregivers" and that they had to carry that title and maintain formal and professional relationships with their clients and people in their care. Nonetheless, they also expressed that due to the nature of the work they were doing and the kind of support that their clientele needed, the relationship could not be only formal but had to be informal as well. The caregivers believed that they needed to connect strongly with their care recipients in order to meet their needs in various aspects of their lives such as their safety and well-being; to reassure them that they are listened to; that they are getting the help they need; that they are being empowered rather than always letting others do things for them. Also, these caregivers believed that through having an informal relationship with this group of people, they could enhance the self-esteem of the people in their care and encourage them to take the small steps needed towards their empowerment and help regain control over their lives once again.

… I take issue at being a formal caregiver as a profession because I think that um

I think that that's a big nursing thing …Um I think that we do provide support to

people so therefore there is that caregiver perspective but I think caregiver is

inherently not a professional relationship. Um I think that there's a component of

the client population that I have very professional relationships with that I think

they get really good care I don't but I don't think that I um would be particularly

considered to be a caregiver per say… (Angelina)

Moreover, some caregivers in the medical sector (doctors and nurses) acknowledged having a formal relationship with individuals in their care where they were obligated to provide equal care and standard support to everyone in their care, but at the same time they felt that care was a personal choice that they would provide to certain people in their care. For example, one of the caregivers stated, "Um, like I had gone to a refugee hearing with one of my clients um which um isn't part of my job description". "Um I did it entirely on my own time. I don't expect to be reimbursed for it. The clinic you know doesn't require me to go, she but that is that I would be fine as as more care giving" (Angelina).

This type of care was beyond their professional caregiving role that they could offer to only those that they would choose. This type of care was based on how the caregiver perceived their relationship with that particular individual and how they felt about them. In this type of relationship, the caregiver had established a strong connection and relationship with that particular client throughout a long period of time, and at the same time, there was no friendship or personal connection between the caregiver and the client. "…I would say that everybody gets like a good quality healthcare from me, and that doesn't get differentiated whether or not I like you or don't like you or or, you know, enjoy your company or not." (Angelina).

In addition, some caregivers who worked in the area of community outreach and/or education perceived their relationships with people in their care as a "support worker not a caregiver", and as an "external caregiver" because they believed that they needed to support care recipients with day to day living activities. For example, these caregivers believed that individuals in their care needed support with income or support with immigration issues, and some felt like they needed to be a voice for them and advocate for them. These caregivers believed that being a support worker rather than a caregiver would benefit these individuals more as they had the ability to do daily living things on their own, but they needed support around the system to make their voice heard. "… I think yeah like I wouldn't have thought of myself as a caregiver I just consider myself as a support worker …" (Dory). Thus, caregivers believed that showing care and being connected with people in their care was very important for building a positive relationship with them.

Finally, other caregivers who worked in the community support sector (social workers) believed that being a "formal caregiver" or an "informal caregiver" was just a title to provide support in every aspect of life for those individual in their care. Some caregivers felt more comfortable describing their relationship with low income and stigmatized HIV positive individuals they were providing care for as being their friends, while at the same time fulfilling their job requirements. "So um I don't necessarily like to say formal or informal. Just someone who's there to look out for somebody else's well-being. Give them um I suppose guidance or suggestions depending on what they are looking for. Um and trying to point them in the right general direction that they want to go…" (Roseanne). These caregivers believed that they needed to look after the well-being of people in their care whether it was emotional, physical, and/ or mental health.

Problems/Issues Linked with Caregiving for Stigmatized People Living with HIV

There were a number of problems and issues associated with providing care for people from low income and stigmatized background living with HIV/AIDS such as: ethical and moral issues, stigma and judgmental attitude, biased and negative opinions, breaking boundaries by caregivers, lack of multi-skilled caregivers, lack of consistency and trust, lack of combined caregiving (formal and informal), limited support and stress management.

Ethical and moral issues settlement was one of the problems that many caregivers were confronted with when they provided care for people living with HIV/AIDS. Some of these caregivers had a negative and biased opinion about this group of people which affected their behavior when working close with HIV/AIDS affected individuals. For example, such caregivers could not establish a positive and truthful relationship with this group of people due to stigma and un-acceptance attached to HIV/AIDS. Also, the caregivers could not show respect to these individuals, thought that care recipient had done something wrong and the disease was somehow the client's fault. Caregivers who had issues with the stigma around HIV/AIDS found it hard and challenging to work close with this group of people, show sympathy and genuine care.

> if somebody wants to go and work for people who are living with HIV and AIDS
> they need to seriously look at the stigma, at what their opinions are about people
> who are living with this illness, and they need to clear that up within themselves
> first, really, ethically you know, and also morally, they need to really settle that
> within themselves…(Molly)

Also, the lack of enough resources and support encountered, explained the breaking boundaries by some of the social workers and outreach workers when they were providing care to stigmatized and low income people living with HIV/AIDS. "I know I overstep some of my boundaries, only because I wanted them to feel, like they're important not just to me but to the

organization." (Jackie). Some of other outreach caregivers highlighted that some organizations that they worked for did have enough staff or/ and resources to deliver the best and needed service on time to people of HIV in their care. Therefore, these caregivers felt a need to go beyond their role and provide support to those people in their care; for example, driving to a clients' house and dropping groceries after working hours. This practice was creating boundary issues among people living with HIV and their caregivers. For people living with HIV this practice increased dependency and more reliance on these caregivers, expecting more and asking for services that were not covered by the organization. Similarly for the caregivers, it was time consuming and hard to manage the clear line of boundary and professionalism, while being all too much exposed to the personal issues of those living with HIV.

"I do know the boundaries, the policy states here, in client services ... if there is way that you can get the client, I know there is many times that clients sat, this is how much they trust me, can you lend me twenty please please, I'll pay you back tomorrow..."(Rita). However, some outreach caregivers stepped over their boundary when they promised people in their care to lend some money to them. To these caregivers, lending money was not an issue and they thought that simply they were supporting those people living with HIV in their care when they were facing financial difficulty. Moreover, boundaries were crossed when there was no clear relationship built between the caregivers and the people living with HIV in their care; or boundaries were stepped over when caregivers did not have enough knowledge about the rules and policies in place at the organization.

A former social worker volunteering as a board member for an AIDS service agency stated that the lack of multi-skilled and well experienced caregivers, able to work in different caregiving settings, was a key issue that some organizations were confronted with while providing service for people living with HIV/AIDS. Multi-skilled caregivers were those

caregivers who had professional knowledge and training in different areas of caregiving such as mental health and well-being, physical health and chronic diseases, cultural and ethnic background knowledge of different clients group under care, and having an insight of low income, stigmatized, and minority population of the society.

Also, a few caregivers in the community support sector reflected their concerns about not having enough numbers of well experienced caregivers. Among the reasons, these caregivers mentioned that providing care for marginalized individuals living with HIV/AIDS was very challenging and draining. Therefore, many experienced caregivers could not hang around for many years and they would leave the field after a couple of working years. Then the new and inexperienced and un-trained caregivers would take over from those experienced caregivers. For the new and inexperienced caregivers, it took a long time to learn how to work with marginalized people living with HIV/AIDS and then to provide proper and quality support. On the other hand, stigmatized and low income individuals living with HIV/AIDS were highly vulnerable and they needed help in broader aspects of their lives. "Somebody that has worked in suicide intervention and prevention to assess whether the suicide risk is high or low, those are, those are the type of people that should be working with people living with HIV and AIDS." (Molly). This observation resonates true as HIV-positive individuals could greatly benefit from caregivers who had a good understanding of grief, palliative care counseling, knowledge of community resources and development, are familiar with mental health problems, and have experience in intervention and prevention skills.

Outreach workers and social workers who provided care to people living with HIV believed that combined caregiving (formal and informal) was lacking in the caregiving environment of HIV/AIDS which was needed "And sometimes I find that I can do more work in the natural support, than I can at the professional because I am limited… I have rules that I need

to follow…" (Molly). Some caregivers stated that combined caregiving practice would improve

the quality of life for people of living with HIV/AIDS because in formal caregiving settings, the

main focus was on medication and treatment of the illness itself and there was no consideration

for other aspects of the clients' life. For example, a number of these caregivers mentioned that

most of the individuals with HIV/AIDS in their care needed support at an emotional and spiritual

level to put their journey of HIV/AIDS and grief at ease.

Moreover, some caregivers in the medical sector such as nurses and outreach workers

believed that working with marginalized people living with HIV/AIDS was a hard task that

required a lot of support and resources in place to better manage the stress and pressure of the

workload. Furthermore, some of the caregivers in the community outreach sector mentioned that

they were not well supported by their organizations, and that these organizations were not well

equipped with proper resources and training sessions. For example, there were no debriefing

sessions for caregivers when managing complex cases, no external supervision for the caregivers

to access a different perspective on their performances and professional development, no

employee assistance program (EAP) services (a work-based program designed to improve the

emotional, mental and general psychological well-being of all employees and includes services

for immediate family members), and/or any recreational activity at work for self-care.

> "Um I I think they they support us in the informal but but I thinkwe all need
>
> formal… I don't see our management coming around and saying may you've had
>
> some really difficult days or clients you know and pats you on the back and say
>
> how are things going its um or anything like that or we've had a rough year; we
>
> should be doing some kind of um release you know have a little party or
>
> something like that." (Will)

Some caregivers in the community support sector stated that building trustworthy relationships with marginalized people living with HIV/AIDS was challenging as they were not communicating transparently with their caregivers. "Many times I tell, hey this doesn't feel right, you're telling me one thing, now you're telling me another. It doesn't fit." (Molly). These caregivers mentioned that marginalized people living with HIV were struggling in different areas of their lives; they lacked the skills to build trust with their caregivers due to asking for favours and services beyond the capacity of the caregivers and the organization. Also, the caregivers could not build a strong connection with this group of people due to the inconsistency in their statements and behaviors.

Risks to Well-Being of Caregivers of People Living with HIV

The majority of the caregivers acknowledged that working with stigmatized and low income people living with HIV/AIDS was highly intense and that they experienced stress, burnout, and potential risk to their mental well-being. . Some caregivers in the community support sector stated that they had experienced and were hit by different types of stressors, mental distress, and grief at numerous times throughout their practice due to being exposed to the problems and issues of vulnerable individuals and particularly to that of stigmatized and low income people living with HIV/AIDS.

> … plus I do my stress release, umm, breathing as well, so that I don't get too anxious or get affected, because it can happen, its happened a couple of times with me… (Molly)

A majority of caregivers indicated that when they established a close relationship with marginalized people living with HIV/AIDS and provided care on a regular basis, their mental well-being was affected and experienced high levels of stress and burnout. The caregivers were

exposed to the problems and struggles of the individuals in their care and knowing a lot about their clientele was affecting their emotional state and putting pressure on them. "…you're sacrificing a piece of yourself to that person and you're connecting. You are carrying that load, that burden… it would consume you." (Molly). Also, these caregivers found it hard when the people in their care told them their stories. Many of the stigmatized and low income people living with HIV/AIDS not only struggled with the illness itself, but were also facing other challenges as well. Isolation, loneliness, no support from family and/or friends, being poor, having no source of income, and suffering from some form of mental illness were common challenges that these people were struggling with on a regular basis.

In addition, most caregivers in the community support sector and community outreach sector believed that being in a caregiving profession for a long time helped them to discern when they were getting too involved emotionally with people in their care, and also to recognize when they were experiencing stress and burnout. However, for new and less experienced caregivers, it was not easy to recognize when they were being overly involved or being impacted by stress or experiencing a low emotional state of mind.

> …But other than that I recognize that, because I've been doing this work for so
> long that I recognize it when it starts affecting me.(Molly)…but I would say
> mostly just from experience and over time. I think that ah I've learned some very
> hard lessons along the way, not here necessarily, but what happens when you're
> too much of a role in somebody's life. (Maggie).

The outreach and social workers who provided care to people living with HIV acknowledged and believed that their mental health and well-being was more protected in professional caregiving settings and less affected than in informal settings. This is because in professional caregiving settings there were fixed hours to work with clients and caregivers were

only obligated to do certain tasks for these clients. "I mean, I don't have an interest in taking work or clients home with me." (Maggie). These caregivers mentioned that they did not need to spend unlimited time with each individual in their care, or visit them at their houses beyond the working hours. Also in formal settings, caregivers were not expected to stay overnight or live with the clients in their care. Maggie said, "… it does allow me to kind of keep myself out of it, at work. And give people all I can during that specified time that I'm employed by the organization, but um but put good boundaries in place so that I don't do more then I should or become more for an individual then I really should be." Whereas, in informal settings, caregivers of people living with HIV/AIDS were involved a lot more in the lives of people in their care and they were spending unlimited hours supporting these clients, which in return exposed these caregivers and put their well-being and mental health at higher risk for stress and emotional distress.

Moreover, in formal settings, social workers noticed that putting in place standard boundaries could protect them to some degree from carrying high loads of stress and the burden of the emotional problems of the individuals in their care living with HIV. In professional settings, some caregivers in community support sector mentioned that they had access to a professional support system which helped these caregivers to deal better with work-related pressure and stress. "…if I have a really high risk or heavy case, or a heavy, just a burden that I feel over someone, I get another mentor, and elder to come and pray with me and then I share how I'm feeling…" (Molly). The professional support system consisted of seeking support from mentors, debriefing with line managers and coworkers, attending counseling, spiritual support, and sharing thoughts and feelings with professional colleagues. "Plus I go into my sweats when it gets really, when it gets really ah tough, I go into my sweat and that is more of a spiritual cleansing process for me, and sometimes I'll do it for all of my clients…" (Molly).

Additionally, some caregivers such as nurses and social workers believed that accessing Employment Assistance Program (EAP) played a significant role in enhancing their mental health, preventing work related stress, and carrying client's negative emotional load. "Oh yeah um I mean I do occasionally use EA. Um over the years like very sporadically I've used them and I found it extremely helpful like when I just sort of am stuck …" (Angelina). Most of the caregivers believed that EAP services provided right directions and guidance when they felt overwhelmed and that nothing seemed to work or move on. Caregivers mentioned that they could easily unload all work-related stress or any other personal negative emotional feelings that were affecting them with the EAP counselors.

Finally, caregivers in medical, community outreach and community support sectors acknowledged the positive role of their own family members, friends, social support teams, and direct line supervisors in relation to their well-being and dealing with overwhelming stress. These caregivers stated that when they felt down or concerned about some people in their care, they would talk to their support circle and express what was happening to them, how they were feeling and what was triggering them. Also, these caregivers mentioned that they were fully mindful of not breaching privacy of the people in their care and they did not mention their names and gender to their family members, friends, or social support team.

> Ah well in my personal life I have great friends and family like I don't go and say oh like this client does that but I'll say like oh like I'll say if I get triggered in some way like ah I just remembered this from you know my own experience. …but if it triggers something my own personal life I'll usually talk to my friends or my family… (Dory)

Stressors Related to Caregiving in the HIV/AIDS Sector

The data revealed that caregivers were well aware of being prone to the pressure and different types of stressors such as burnout, compassion fatigue, and vicarious traumatization due to the nature of the work they do. "I'm always aware of that so what I do for myself is I do the smudge, and many times I go to my mentors, I have my own support system in place, if I have a really high risk or heavy case…"(Molly).

Moreover, all of the caregivers did not reflect separately on compassion fatigue and vicarious traumatization but they related to them as stress, getting infected, experiencing trauma and PTSD symptoms, carrying burden and load of their client's negative emotions and feelings, being too anxious or unwell, and mental distress. For example, Molly stated, "And I asked her what happened, she said he left us, not even a year after you had left the province, he hung himself. And that really affected me." By hearing this news Molly faced emotional distress and was highly prone to experiencing trauma and PTSD. "…there are traumatic events that happened to us that um people have difficulty processing. I have witnessed and been involved in traumatic situations and um you know had all the PTSD symptoms like not sleeping, jittery and not been able to really be able to process ..." (Ellen).

Some caregivers in community support sector (social workers) reflected that they were exposed to the inappropriate behavior of some workers in other caregiving setting with children in their care and these caregivers did not pay attention to children's safety and well-being. Exposure to this situation was hard for these caregivers as they were getting concerned about these children's safety and proper treatment and in return these caregivers felt frustrated and helpless. "I remember being really depressed after one of our clients passed away and thinking about her kids that she left behind... It made me realize more so than ever working here that some kids never have a hope in fucking hell of not being hurt. I need the day off because I've

burn out from this…" (Maggie). Moreover, the outreach workers and the caregivers in community support sector witnessed intense incidents such as deaths of people HIV positive individuals whom they were providing care for, and as well as witnessing their kids left behind and becoming vulnerable and ending up in the sex trade and being sexually abused. These caregivers mentioned that when people in their care died, it triggered personal life issues for them also, and it reminded them of having a bit of rapport with these people. Thus, such cruel and harsh situations and realities were very stressful for these caregivers in the HIV/AIDS sector since they could not prevent death for these people nor could they protect their children from being abused and hurt.

In addition, some caregivers in the community support sector (social workers) stated that they experienced stress and burnout every now and then when providing support and care. "Ah I had a client who um harmed himself… it can be very very bad so I do get triggered just cus um sometimes I witness the same myself, different clients going through the same thing. Ah and it's hard and like you know when I see clients getting abused by their landlords" (Dory). Some people living with HIV in their care were telling them about how they were going to harm themselves since they could no longer face the challenges and hardships of life and were feeling hopeless. For example, on one occasion, an individual living with HIV narrated the way he was going to harm himself and it was exactly the same way as this other individual had hurt himself. Thus, when these caregivers were exposed to the same kind of situations over and over, they found it very sad and overwhelming as past incidents of people harming themselves were reminders to them.

Most of the caregivers stated that working with HIV positive individuals was challenging at times and making them emotionally distressed. Mostly because marginalized people with HIV/AIDS were not only suffering from the infection, its complications, and negative side

effects of treatment, but also having difficulty in recovering from other illnesses, as well as

having to deal with different forms of distress such as financial, physical, emotional, and sexual

abuse. For example, one of the caregivers stated that working with a young HIV positive child

was very hard and stressful and that on one particular occasion they had had to call the crisis line

to get help and release the emotional stress and burden. The caregiver witnessed this particular

child being abused on a regular basis at his/her household. The young child was abused sexually

and "in every possible way that one can think of." Moreover, this child was very ill as a result of

suffering from HIV/AIDS positive and addiction problems. The caregiver witnessed that the

client was shaking all the time and their hands were trembling. Also, she could not walk at a

normal pace and she had to hold on to the wall to walk and she walked really slowly.

Some outreach caregivers indicated that high staff turnover was caused by experiencing

burnout and compassion fatigue. The caregivers are exposed on a daily basis to people's

suffering, their physical illness and pain; listening to dramatic and upsetting life stories and thus

they experience high levels of stress and anxiety, nightmares, anger, low mood, and feeling

drained.

> …if you're so stressed out with why this person is getting agitated or, the
>
> nightmares that come with it,…I think it's the staff turnover…Because we go
>
> through so much trauma being at (agency). There's you know a lot of losses, and
>
> even though it's informal you're human. And so you are feeling all the things that
>
> you know it it's loss for all of us when someone passes away. (Rita)

Moreover, some caregivers in community outreach and/or education sector (e.g., outreach

workers) revealed that new and inexperienced caregivers were at higher risk of burnout and

stress as they were not realizing when their mental health was getting affected and/or how to

detach their personal emotions from the heavy burden of emotional distress of people in their

care. These new and inexperienced caregivers often could not cope with the stress and burnout and thought that the only way to remain healthy and recover was to change their profession. Thus, these caregivers would leave the profession earlier than those caregivers who were more experienced and worked for a longer period of time.

Finally, the outreach caregivers indicated that when they were providing care services and had direct interaction with people living with HIV in their care, then they were exposed to all kinds of situations that these people were at. "I get sad a lot at different situations. I get frustrated with things that are out of my control." (Grace) In addition, listening to true and painful stories of racism experienced by people living with HIV, and being rejected in the community because of their HIV status was one of the common experiences that some of the caregivers had experienced them personally as well. "Um if I hear clients talking about racism or you know like like um you know that triggers me to and to feel frustrated because I know I've experienced it myself."(Dory). Thus, for these caregivers, hearing such bitter stories triggered personal harsh experiences which in return affected the mental health and emotional well-being of the caregivers.

Implication of Caregiving Boundaries in Formal Settings for Caregivers of People Living with HIV

Some of caregivers reported that in the formal settings of caregiving, employers and staff have established formal and professional boundaries. These boundaries had been established through rules in place, policies, and guidelines. Both staff and the caregivers were bound by these boundaries while providing services and support to people living with HIV in their care. The caregivers in the community support sector (social workers) stated that boundaries were taught to them while they were receiving formal education in the field of social work and in any

other caregiving field through universities. Also, caregivers mentioned that boundaries were introduced in professional caregiving settings through workshops, trainings, and staff meetings.

> When you're a professional you are kind of at an arm's length, where, we are taught in university or during our practice that we're to umm, be at an arm's length and not to get mixed up you need to be objective. I do know the boundaries, the policy states here, in client services, what you can do and what you cannot (Molly)

The data revealed that boundaries were there to protect both clients and the caregivers. The caregivers needed to establish them at the very beginning of establishing a working relationship with people living with HIV in their care, so they could establish and maintain trust, mutual respect, and maintain professional relationships with these people in their care. "This one is more of ahh, forming and setting policy and making decision in terms of what type of services you want to provide…So I'm still bound by my ethics in social work as well and I tell them well if you want respect from me well you have to respect me."(Molly).The purpose behind establishing and maintaining boundaries was to offer safe and secure services, setting up clear expectations, and preserving confidentiality.

Most of the caregivers stated that they could establish and maintain boundaries through avoiding personal interactions in any form with people living with HIV in their care. For example, they needed to avoid making friends with people living with HIV in their care and/or not to establish an intimate relationship with them. As well, outreach caregivers and social workers mentioned that offering personal favors such as lending money, or helping clients after working hours and providing them with their personal contact details such as phone numbers and home addresses were prohibited by the organization that they were working for. "I have limitations in the sense of like I said I wouldn't go and clean a client's home, that wouldn't be

appropriate I'm here as a formal caregiver." (Jackie). Also, not sharing and/or transferring

personal feelings about work or about another care-receiver with people living with HIV in care

were clear set boundaries that all staff and caregivers needed to follow and respect.

> I have a lot of people ask me intimate questions and then say oh you know is that
>
> okay or and just very gently I have to say it's, you know I can't respond to that.
>
> (Jackie)…can you lend me twenty please please, I'll pay you back tomorrow, and
>
> I was like but sorry under policy I cannot do that. (Rita)

Some caregivers in the medical sector openly stated that they did not have any interest in

working after hours with people living with HIV in their care or taking work with them home.

Also the caregivers appreciated having pre-set boundaries in the workplace as the boundaries

helped them to keep themselves at some distance not to get too involved with individuals in their

care. It also helped not to do more work for these individuals beyond their responsibilities.

In addition, outreach caregivers and social workers mentioned that they drew different

boundary lines with different people living with HIV in their care and boundaries were never

consistent from person to person. For example, some of these caregivers stated that there would

be things that they would do for some individuals that they would not do for other individuals,

and such support totally depended on how comfortable they felt with that particular person.

These caregivers mentioned that it depended if they had known the individuals in their care for

long time and had established a trustworthy relationship with them.

Some of the outreach caregivers explained that they learned over time how to establish

and maintain boundaries at work with people in their care as boundaries were not mentioned in

their job descriptions. These caregivers stated that after they were hit or caught up in some

complicated situations with individuals in their care or when they felt stuck and too much

involved with certain people living with HIV in their care, they had learned how to establish

better boundaries. These caregivers mentioned that boundaries were huge and knowing them all and maintaining them were not possible at all times. But the caregivers stated that they learned through practice and experiencing something new at work every now and then.

> A combination, but I would say mostly just from experience and over time. I think that ah I've learned some very hard lessons along the way, not here necessarily, but what happens when you're too much of a role in somebody's life. I've had clients who ask me, you know, this, that, can you do this for me can you do that for me. And mostly its just common sense but some of it like you know I will absolutely um utilize the fact the I work in the organization and say no to that no I can't do that. (Maggie)

Some of the caregivers in the community support sector and community outreach sector mentioned that sometimes boundaries were compromised due to the workload, demands of people at care, and making mistakes. Boundaries were also learned though making mistakes and trying to fix them or not to repeat them next time.

Most of the caregivers reported that they drew clear boundaries around their safety and home space while caring for people living with HIV. This meant that caregivers would not and did not provide caregiving support when they felt that their life and safety was at risk. For example, the caregivers in the community support sector and community outreach sector mentioned that before visiting people living with HIV at their homes, they made sure that it was safe enough for them to go into their houses. Also, some of outreach caregivers stated that they never invited individuals living with HIV in their care to their own houses, or provided support over the phone outside of working hours.

> Um sometimes like I've had a a client phone me at home once for something cus they were lonely or whatever and I said you can't be phoning me at home, I can't

talk to you at home. Because work is work and my home life is my home life and

we can't cross those lines. (Flo)

A number of caregivers mentioned that they understood the importance of boundaries and

not being the primary person in the lives of those individuals living with HIV that they provided

care for. Some caregivers in the community support sector stated that they could not be the "all

to end" person for people in their care. This meant that these caregivers did not want be the only

and the main person in the lives of these people, where they would solely rely on them. These

caregivers mentioned that they drew a clear boundary with people living with HIV in their care

so that care recipient did not completely rely on their caregivers, but instead tried to link them

with other services. Also the caregivers believed that people in their care were quite resilient and

that they could do a lot of things on their own and they did not need help from their caregivers.

The caregivers believed that they needed to work on the independence and self-sufficiency skills

of individuals living with HIV through creating boundaries and drawing a clear line on what

services and support they could offer to these clients and what was not an option.

Some outreach caregivers acknowledged and understood that they could be friendly and

at the same time, maintain a supporter-care receiver relationship clearly defined with people

living with HIV without stepping over their boundary. However, these caregivers noticed that

these boundaries line between caregivers and the people living with HIV was not clear for some

other caregivers who without well-established boundaries were either becoming too close with

clients and tried to fix their lives for them or they became too strict and very distant with these

people which was affecting the quality of service and support provided.

Some caregivers in the medical sector (nurses and physicians) stated that they needed to

be very clear on boundaries with individuals in their care in order to maintain professionalism.

"… if you give them money it changes the dynamics of the relationship, but if you put up a big

sign saying we can't give you money that changes the dynamics so it its yeah I don't think you

can." (Will) These caregivers mentioned that there was a very fine line between them and the

people in their care and if this line was crossed, the caregivers would remind these individuals

that they were not friends and it was all about work and professional relationship between them.

>Ah you know like somebody saying oh thanks for doing this for me and I wanna
>
>invite you out for supper oh we can't do that. I'm your nurse these are the
>
>boundaries that we have to set forth. Oh but you've done so much for me then you
>
>say, "I'm doing this because I'm your nurse" and I'm able to actually hide behind
>
>that to protect myself and and not to go further than I should if I ever I'm ever lost
>
>with my boundaries I can say oh I'm your nurses this is, this is our goal this is our
>
>my role and I won't break those. (Will)

To caregivers in the medical sector (nurses and physicians) the boundaries were clear and they

were able to practice and maintain them.

Benefits of Boundaries for Caregivers of People Living with HIV

The majority of the caregivers expressed that forming boundaries and maintaining them

with the people living with HIV in their care were very beneficial and important for them, and

helped them to provide consistent service to these people. Some of the caregivers mentioned that

in formal settings (as compared to informal settings of caregiving), there were clear boundaries

that protected caregivers in different ways. For example, in formal settings, when people living

with HIV at care asked their caregivers for a stay overnight at their places or providing support

after working hours, the caregivers felt confident and comfortable to refuse and tell clients that

they could not do that and providing such services were not allowed by their organization. These

caregivers mentioned that such boundaries provided a "wall of security" where they could hide

behind it without hurting the feelings and emotions of the people in their care. Whereas, most of the caregivers stated that when they were providing caregiving services in informal settings to family members and friends, it would not have been possible and they would not feel comfortable saying no to their closed ones when they were asked for something similar, as there was no " wall of security" to protect them.

Some caregivers in the medical sector, community support sector, and community outreach sector indicated that keeping boundaries with marginalized people living with HIV/AIDS helped them to stay professional and maintain consistency with each individual in their care. For instance, on some occasions these caregivers were asked by a few individuals to be picked up and dropped off at some places, but thanks to having clear boundaries in place, they were able to say no and explain to them that they could not do it as it was part of their organization's rule not to offer personal favours to anyone. Some of these caregivers mentioned that at times people living with HIV in their care invited them to their houses for dinner to extend their appreciation as they felt well supported. These care recipients thought that it was a good way of paying back their caregivers, but the caregivers were able to use boundaries to explain it was not a favor but part of their job and stated they were not allowed by the organization to accept such invitations.

> …but I think also something that I do wanna share is that the consistency, like I've noticed in the twelve years that if I am consistent with each person; solid, this is my response, this is why, you know it's nothing personal, it's about boundaries, it's about keeping you healthy, keeping me healthy you know enmeshment, people get that, they hear that. (Jackie)

Boundaries in place benefited the caregivers to maintain their distance and not to get too involved with clients and become the centre of their lives. Some of the caregivers expressed that

most of the people living with HIV/AIDS they worked with, were lonely and did not have any family or friends; thus, they were trying to establish a close relationship with their caregivers and become friends with them. But having rules and policies about boundaries in their workplace helped these caregivers to tell the individuals in their care that they could only maintain a formal relationship and avoid forming friendships with them. For example, at one occasion Grace mentioned, "I mean I speak directly to people, as directly as I can. And sometimes when the boundary gets a little grey or whatever I just straight up say, you know what, I'd like to be that for you, but I can't you know. If I do that I would lose my job, do you want me to lose my job, no, okay thank you, you know."

In addition, most of the caregivers acknowledged the benefit of protection and safety for both caregivers and people living with HIV in their care, when there were clear boundaries in place and caregivers practiced them. For example, these caregivers mentioned that they did not disclose and talk about personal issues, emotions about or anything or anyone with those they provided care to, and when they were asked personal questions about age, marital status and so on, caregivers did not provide them with such information. The majority of caregivers mentioned that the people living with HIV in their care, after learning about workplace boundaries, respected them well and stopped asking personal questions. This helped both the caregivers and the care-receivers to feel comfortable with each other, to continue working together, and to maintain a healthy practice.

> And not to transfer any feelings on to the person that we may have personally, so
> that's the type of barrier that's there already when you're doing professional
> caregiving. And I think its more protection for the professional caregiver to have
> that boundary set there, so that they're not carrying that load, that burden. (Molly)

Moreover, some caregivers in the medical sector, community support sector, and community outreach sector stated that having boundaries in place helped them to prevent any mental and emotional distress as a result of not having a close contact with the people in their care. Boundaries helped them to prevent emotional damage and detach their personal feelings that otherwise could have caused stress and burnout. "I accept that there are boundaries and I understand why they're there. They are there for reasons that…you know that old term burnout, so burnout doesn't happen, so damage doesn't happen to them or myself." (Molly). Most of the caregivers believed that maintaining boundaries enabled them to establish trust and healthy relationships with the people they provided care to.

> … they trust you, if you can go into the room with them, you know they really trust you to be there for them, and there is some who are really scared that they don't even know what's happening, so you're going to be there and say okay, well this is so and so, I've worked with them, you're expressing that kind of feeling that okay. Work with other clients, working, in the process of letting the client know that you're not just here because it's the benefit of just being there, or another pay check it's not, it's all about caring for that person. (Rita)

Thus, balancing and managing to detach personal emotions helped caregivers to remain healthy and better support these individuals. Also, these caregivers mentioned that detaching their personal feelings helped not to quit their work and stay longer in the caregiving field as compared to other caregivers who could not manage the stress and had to quit or change their roles. "Well if you're if you're the kind of person like me that likes to to see people succeed and cares about people genuinely um you worry about people, but you, but you can't make their pile of stuff your pile of stuff. You have to leave it here otherwise it will just eat you up."(Flo).

Finally, some caregivers stated that establishing boundaries with people in their care was beneficial, in the sense that they empowered people living with HIV/AIDS to become more independent. "You don't want to create dependency; I don't want anyone being co-dependent on me." (Molly)

Many of these clients were able to become independent and self-sufficient in numerous ways and did not ask their caregivers for support. Moreover, boundaries helped the caregivers to enable people in their care not to have or develop unrealistic expectations. Also boundaries helped to avoid "give and take" relationships with people in their care, mostly those who were using drugs, so they would not ask for money to supply drugs for themselves and then try to return the favor by inviting these caregivers to their circle on different occasions.

> And so sometimes when they're testing, they'll stop and even say that's right you have said before you cannot do this. It is a working relationship that has to eventually end. And that doesn't mean in a negative way, but end as in the person becomes empowered, um independent and is able to access their support elsewhere within their community. (Jackie)

Obstacles and Limitations to Boundaries for Caregivers of People Living with HIV

In the professional caregiving settings, some caregivers in community outreach sector and community support sector indicated that boundaries pose a lot of limitations which left people living with HIV in their care with less support and limited access to resources. One of the limitations was that people living with HIV were not supported in critical and desperate situations. For instance, in one occasion, an HIV positive individual needed support after working hours and needed to talk to their caregivers on the phone as they were feeling lonely and emotionally run down. Although, the caregiver could provide such support, they had to cut off

the phone and stated, "you can't be phoning me at home, I can't talk to you at home. Because work is work and my home life is my home life and we can't cross those lines."(Flo)

In addition, workplace boundaries created limitations and less room for caregivers and people living with HIV in their care to connect well and establish a strong relationship. Some of the caregivers in the community support sector (e.g. social workers) mentioned that they could not offer emotional support and spiritual support to people in their care. The caregivers felt that on a few occasions they had wanted to help some individuals living with HIV in their care, spend more time and listen to their life stories and be an emotional support for them. For instance, these caregivers wanted to go with them to their spiritual ceremonies and practices to uplift their spirits and make them feel better. However, due to organizational boundaries they could not do any of these things, and the caregivers had to tell these individuals that they did not have time for such activities and they needed to maintain work-related boundaries with them.

In addition, one of the most negative aspects of boundaries in professional caregiving settings was that they were imposed on the individuals in care, leaving these clients with no options and thus, these individuals felt not well supported and left behind. For example, sometimes people needed a lift to some places for which public transportation was not available and they could only get there by a car. The clients were struggling to get help with a ride, they could not ask anyone, and not even their caregivers could drive them.

In professional caregiving settings, most of the caregivers noticed that the strict boundaries related to not providing financial support to people living with HIV in their care and that was also one of the problems that both caregivers and the care-receivers faced. Some caregivers in the community outreach sector expressed concern that some of the individuals living with HIV in their care were financially very unstable and at times needed immediate support but they could not help them. For example, on a few occasions the people living with

HIV asked their caregivers to lend them some small amount of money for food and groceries or bus tickets but the caregivers could not give them money even though they wanted to. The caregivers felt bad about not being able to give a hand to these clients due to work related boundaries and the people at their care felt unsupported and had no one to ask for help. "I just hate that, where we would be boxed in, it's not part of my job. Cause I don't wanna close doors for people… Slam doors. I don't lend money it's against you know that policies of Nine Circles." (Flo).The caregivers stated that if such boundaries were not in place, they would have supported these people and given them the amount they asked for.

Moreover, most of caregivers raised concerns around organizational limitations and boundaries that affect their flexibility in establishing strong relationships with people in their care. For instance, some outreach caregivers and social workers mentioned that a few times they wanted to become friends with some people in their care and wanted to offer more support such as take them out and spend more time with them, and/or buy them things or gifts on special occasions, and invite them to their houses. However, firm boundaries at work did not allow them to establish such a relationship.

> I have rules that I need to follow, my employer pays me…because I was limited by policies and umm, just the way the services were provided… (Molly)…or someone who's you know just very, very intimate and special to them. That makes it very difficult with boundaries and relating to people that, cause it's not a friendship. It is a working relationship that has to eventually end. (Jackie)

Moreover, some of the outreach caregivers and social workers mentioned that they could not establish long-term and personal relationships with people living with HIV in their care due to organizational boundaries that they had to follow. "…or someone who's you know just very, very intimate and special to them. That makes it very difficult with boundaries and relating to

people that, cause it's not a friendship. It is a working relationship that has to eventually end."

(Jackie). Thus, the relationships between these caregivers and people living with HIV had to be

basic and short term. On the other hand, the people living with HIV did not like or wanted to

keep such short and basic type of relationships and wanted long-term and strong relationships

with their caregivers, because for them it was about building on their social support network and

having someone in their lives.

In the professional setting, most of the caregivers stated they are not allowed to exchange

personal contact details such as phone number and home address with people living with HIV in

their care. The outreach caregivers and social workers mentioned that such boundaries limited

support and care for stigmatized and low income people living with HIV/AIDS and they felt

disadvantaged at times when they needed to contact their caregivers outside work environment.

On the other hand, these caregivers stated that in the informal support network, there were less or

no boundaries; thus, it would allow the caregivers to offer unlimited support at any time to

people.

> I find that I was providing a lot of emotional support to him yes, and also helping
>
> him, encouraging him, giving him a lot of encouragement, and a lot of spiritual
>
> advice as well. I was committed to helping him to have a safe journey into the
>
> spirit world. (Molly)An informal caregiver I feel has less boundaries to kind of
>
> have to maintain, … like as an informal caregiver I might ah drive people to
>
> places, clean their home, I would have no issues doing certain things, cleaning
>
> their body. As a formal caregiver - for me I have a lot of boundaries so that
>
> wouldn't be possible. (Jackie)

Finally, some of the outreach caregivers stated that too structured boundaries and rules

were limiting advocacy and support for people living with HIV in their care. For example, some

of these caregivers stated that they had witnessed situations where caregivers were not willing to advocate on behalf of those people in their care and would say, "I can't do that, it is not part of my job."(Flo). On the other hand, these clients living with HIV were feeling uncomfortable with such boundaries and felt there was no support or a positive relationship between them and their caregivers. Thus, such boundaries were creating a big gap between the caregivers and the people living with HIV in their care as they did not feel well supported at times.

Challenges That Boundaries Pose on Caregivers of People Living with HIV

All of the caregivers reported that establishing and maintaining professional boundaries was one of the challenges that they faced through working and providing care for marginalized people living with HIV/AIDS. Mostly, these caregivers felt that they needed to step beyond their role and help these people during crisis. For example, some of the outreach caregivers and nurses believed that they needed to help those individuals who were suicidal and take them to hospitals and connect them with mental health professionals or when otherwise the risk of harm was too serious. However, there was no one to provide such support for suicidal people especially during the long weekend. Thus, mostly these caregivers offered such help on a volunteer basis and after working hours.

Other caregivers in the community support sector found complying with boundaries in the workplace very challenging especially when they were caring and providing support to former colleagues or friends who became their current clients. These caregivers stated that because of personal ethics and beliefs they felt obligated to help these people as much as possible and felt they could not say no to colleagues and friends, and helped them beyond their role and requirements of their employers. On the other hand, in such situations these colleagues and friends expected their caregivers to be fully supportive as they did not see them only as their

caregivers, but also as their friends. Also, these caregivers stated that they could not maintain boundaries with such group of people in their care when they had social gatherings such as dinner parties at home or socializing with friends after work and going for coffee.

Some of the outreach and community support sectors' caregivers believed that boundaries were not feasible to be maintained in the workplace and they needed to cross them due to the lack of proper community caregiving systems in place. These caregivers mentioned that if there were enough support systems in place and all needs of low income and stigmatized people living with HIV/AIDS were met, then they would not have crossed the boundaries and maintaining boundaries would not have been a challenge. Another challenge that these caregivers faced was that they had to change jobs or roles within organizations when they had crossed their boundaries a few times.

> In professional life it is, it is difficult if someone comes in and they say I'm hungry, you know and I'm not supposed to go out there and buy them a meal. That, that's hard to stick with you know so more - definitely more difficult. And I think people push boundaries, like I said as the intimacy increases in therapy and doing work. (Jackie).

These caregivers stated that it was very hard for them to hold onto policies in place when they recognized a need for pushing boundaries and offering support beyond their role to the people in their care.

Caregivers in the community support and community outreach sectors believed that it was very challenging for them to maintain limited contact with people living with HIV in their care and offer them limited support in professional caregiving settings because for these caregivers there was a conflict between their personal beliefs and ethics and organizational principles. "I often find some of those policies are contradictory, like in our theories and practice

of work that we are trained to do, your first, your told to help others, that you're there to help them, but they put policies in place, and rules in place where they inhibit you… from helping…I do not like these polices… I believe in helping and to be there for your clients…" (Ellen). These caregivers believed that it was important to keep a close contact with people in their care so they could provide a wide range of support without boundary limitations, especially because marginalized people living with HIV/AIDS were more vulnerable and needed a lot of support. Also, many of these clients were under care for a long period of time with the same caregivers who knew a lot about them and their issues; therefore, these caregivers were happy to provide extra support to them beyond their job and role requirements.

Moreover, these caregivers indicated that creating balance between personal interest and organizational boundaries was hard and challenging. At times they were interested to create a more close and personal relationships with the people in their care. " Sometimes you do wanna cross boundaries or get more involved or you know there's people I meet that I enjoy tremendously, would love to be friends with them; can't do that." (Jackie). In addition, these caregivers deemed that when they were providing care for people they knew beforehand or were their family members, then maintaining boundaries was more challenging and not feasible."I found it very difficult, very difficult to balance… what are you going to say, "I'm related to you I can't help you". There's no way I'm going to say that to anyone, any of my relations, and my friends well…" (Molly)

In addition, some caregivers in the medical sector (nurses and physicians) expressed that maintaining boundaries was challenging because it created a barrier in building trust or caused to destroy the strong and trustworthy relationship that had been built over time. For example, for these caregivers it was necessary to obtain detailed information about the personal lives of people living with HIV in their care, including learning about their sexual life. These

requirements had as a consequence, that the people living with HIV in their care would at times also want to know about their caregivers' lives and their sexuality. When caregivers refused to provide such information about themselves, it offended these clients. For instance, on one occasion, an individual living with HIV assumed that his caregiver was also a gay man and that is why he was well connected with him and they had a good relationship. However, as soon as this individual living with HIV found out that his caregiver was not gay but a straight man, he felt bad about it and it was like a slap to his face. Thus, the caregivers in the medical sector (nurses and physicians) stated that establishing and maintaining boundaries around their sexual orientation was challenging.

> We want to dig and prod and get everything out of our client and yet we don't share anything. Um that's that's another part of the boundary issue. I had one client who said I've never had um I've never had a good relationship with a gay man and so when I said, "I am straight." He, it it floored him, it was like all this time I thought that I was doing so well in in establishing this relationship with somebody who's gay … (Will).

CHAPTER FIVE

Discussion

Through personal interviews with formal caregivers, this study looked at the well-being of formal caregivers who provided care to stigmatized and low income people living with HIV/AIDS in the Manitoba and Saskatchewan provinces of Canada. Also, there was an examination of how formal caregivers perceived their relationship with people living with HIV that they provided care to. The findings reflected that the caregivers were confronted with and experienced stressors such as burnout, compassion fatigue, and secondary traumatic stress due to having a direct and close relationship with marginalized people living with HIV/AIDS in their care. This was consistent with what Sabo (2006) and Alta C van Dyk (2007) found; that those caregivers who provided care for people with chronic diseases such as HIV/AIDS, and survivors of traumatic experiences were exposed to a number of stressors such as burnout, compassion fatigue, compassion satisfaction, and vicarious traumatization. According to Sabo (2006) nurses and formal caregivers were exposed to higher levels of compassion fatigue and burnout in the workplace due to experiencing intense levels of stress. These authors highlighted a number of factors that impact occupational stress and compassion fatigue, such as relevant professional training, experience in social work, social support, strain of empathic work with vulnerable groups of people, and career changes (Sabo, 2006; Alta C van Dyk, 2007).

It is important to acknowledge that the literature review and the research questions focus on different types of stressors such as burnout, compassion fatigue, and post traumatic disorder in relation to the caregivers in HIV/AIDS caregiving sector and their mental health well-being. The findings on boundaries for caregivers in the HIV/AIDS caregiving sector provided responds which are aligned with the existing literature. The findings brought out a hidden connection

between boundaries and different types of stressors in the HIV/AIDS caregiving sector. It found that having proper boundaries in place could reduce and prevent the chances of being affected by any kind of stressors; while not having boundaries in the workplace could result in high level of stressors such as compassion fatigue and post traumatic disorder. In the formal caregiving setting, having clear boundaries in place reduced and/or prevented the occurrence of different types of stressors such as burnout, compassion fatigue, and post traumatic disorder for caregivers. In other words, the organizational boundaries in place helped caregivers not to get involved emotionally, and maintain their mental health well-being while providing care for the people living with HIV. On the other hand, having no boundaries in caregiving settings or not maintaining them while providing care to people living with HIV put the mental health and well-being of caregivers at higher risk of being affected by different types of stressors. This was the case because caregiving for low income and stigmatized individuals living with HIV/AIDS means having to deal with other complex issues such as poverty, isolation, stigma of HIV/AIDS. The findings revealed that boundaries were there to protect the caregivers; thus, it is important to acknowledge the importance of boundaries in the HIV/AIDS caregiving settings and its direct relation with caregivers' well-being and mental health. As well, a majority of the caregivers appreciated having these boundaries in their workplace as it helped them to keep themselves at some distance with clients and not get too involved with the individuals in their care.

The findings revealed that caregivers in the medical sector (e.g. doctors and nurses) compared to the caregivers in community support sector (e.g. social workers) and community outreach sector (e.g. outreach workers) perceived their relationship with people living with HIV differently. For caregivers in the medical sector, this relationship was formal and limited to their responsibility within their organization; whereas caregivers in the community support and community outreach sector, perceived the relationship more informally and intimate and they

wanted to help people living with HIV under their care beyond their roles and responsibilities, bring them comfort and putting them at ease.

The findings suggested that most of the caregivers acknowledged that they had a very important role in the lives of people in their care as they were providing very meaningful support and maintaining a direct relationship with them. Furthermore, an interesting finding was that in most cases the caregivers in the community support and community outreach sectors were the main and central characters in the lives of marginalized people living with HIV/AIDS. Among other reasons, one was that care-receivers were able to trust their caregivers about not disclosing their HIV status. Furthermore, many of these individuals did not have anyone else to ask for help. As Mallinson et al. (2007) described, a care provider has an important role as either a facilitator or a barrier in the process of engagement and retention of people living with HIV/AIDS in HIV primary medical facilities. Research has shown that "patient-provider relationships" and "patient satisfaction with care" are mutually associated. Furthermore, people living with HIV/AIDS prefer to be in the care of formal caregivers whom they can trust, demonstrate respect and care, and possess effective communicating skills. This group of people will seek help from those health care providers who go above and beyond their role to develop relationships, to treat them as unique human beings, and advocate for them (Mallinson et al., 2007). The findings suggested that these caregivers hold such a crucial role for the individuals living with HIV/AIDS in their care, that they often experienced stress, and at times found difficult to deal with the stress of their role. The findings are consistent with a number of existing studies (Bellani et al., 1996; Wood & Killin, 2007; Adams et al., 2006) showing that caregivers go through emotional exhaustion, occupational stress, burnout, and negative psychological effects as a result of caring for people living with HIV/AIDS.

In addition, the findings suggested that occupational stress can be prevented and reduced through a number of organizational cultural factors and support system at the workplace. Some caregivers in the medical sector (e.g. nurses) and community support sector (e.g. social workers) stated that getting involved in the decision making at the organizational level, debriefing with coworkers and line managers, offering support and receiving support from other team members positively contributed to reduce the amount of pressure and stress at the workplace. This finding was aligned with the study by Glase, Zamanou and Hacker (1987) which also showed that organizational culture, meaning shared expectations for behaviour in the organization, and organizational cultural factors such as effective teamwork, involvement in organizational decision-making, and social undermining, can contribute to reduce occupational stress and burnout for caregivers.

The findings showed that the caregivers in community support sector (e.g. social workers) and community outreach sector (e.g. outreach workers) perceived their relationship with those they provided care for, as a supporter and a helper. These caregivers acknowledged having a formal relationship with people in their care but at the same time, they emphasized the need to have a strong and a more connected relationship with people in their care. Also, the caregivers mentioned that in professional caregiving settings, their relationship with stigmatized and low income people living with HIV/AIDS was very limited, and thus they could not provide enough support in different aspects of their lives. However, there are few studies on how caregivers in HIV/AIDS sector perceive their relationships with marginalized people living with HIV/AIDS. Mostly, scholars have focused on the kind of tasks and supports that are provided by caregivers to the people, but not how they perceive their relationships with their care-receivers (Mignone et al., 2011)

Moreover, an important finding was that these caregivers perceived a need for a combined caregiving system where people in care could have access to both formal and informal caregiving. The combined caregiving system could eliminate the existing limitation and gaps and could offer a wide range of support to people in their care. Also, the findings indicated that caregivers in some caregiving settings were the major source of social support for marginalized people living with HIV/AIDS, providing emotional, physical, social, and spiritual support. However, such support was limited and it was only delivered in a few caregiving settings.

Most caregivers emphasized that having such a caregiving and social support system within the caregiving setting would improve the health and overall well-being of people in care. On the other hand, the caregivers acknowledged the fact that such caregiving system was very expensive to run and not all caregivers have the capacity or skills to offers such a meaningful support to people in their care. The caregivers in the community support and community outreach sectors indicated that the lack of multi-skilled caregivers with experience in different areas such as mental health and well-being, crisis intervention and homelessness, social and spiritual engagement, was an issue in most caregiving settings

An interesting find was that a majority of the caregivers in community support sector and community outreach sector expressed a willingness to offer help and support beyond their responsibilities to the people in their care when the organization allowed them. One of the reasons was that caregivers had built a strong connection with their clients and were well aware of their situation and needs. Some of these caregivers mentioned they were fine with providing assistance with household tasks such as food preparation, helping clients with their mobility needs, assisting with chores and/or preparing comfortable beds with cushions and pillows. The findings suggested that such involvement and support was lacking in the formal settings of caregiving, however there was a big need for such care as more involvement could solve minor

problems and could make individuals in care more at ease. Research has also shown that in hospitals and other caregiving settings, caregivers invested much of their time on advocating for people living with HIV/AIDS, but not meeting their personal and domestic needs (Mignone et al., 2011).

The findings corroborated that all caregivers were clear about boundaries in formal caregiving settings and understood the need to follow them. Caregivers acknowledged that compared to boundaries in formal settings, there were no boundaries in informal caregiving settings, making it easier for them to establish a close relationship with people in their care and work with them without limitations and restrictions. An interesting fact that emerged was that most of formal caregivers in community support and community outreach sectors did not like the idea of having boundaries with people in their care as boundaries limited their movement and the kind of relationship they wanted to establish with some of the people in their care.

On the other hand, a majority of caregivers acknowledged that providing care for marginalized people living with HIV/AIDS was challenging for different reasons. For instance, dealing with the stigma of the disease and maintaining confidentiality of HIV status was difficult to face on a daily basis at the workplace or in the society. Some caregivers had come across other caregivers who were not comfortable to work with people of HIV/AIDS and these were a big turning point for them to leave caregiving. This part of the findings was very similar to that of Alta C van Dyk (2007) who found that the majority of caregivers believed that HIV/AIDS caregiving was caught up in stigma and confidentiality issues. These caregivers found it very challenging to manage the stigma, and eventually they would leave their profession and choose not to provide caregiving support to individuals with HIV/AIDS.

In formal settings and at the organizational level, there were sets of rules and policies that prevented the broader and flexible relationships of caregivers with the people living with HIV in

their care. These rules and policies created boundaries between the caregivers and the people in their care. Boundaries were perceived both as positive and negative by the caregivers as they could prevent stress and burnout because they could hide behind them; and at the same time, these boundaries were preventing the caregivers from offering more support to their clients living with HIV/AIDS.

A majority of the caregivers acknowledged the importance of having and maintaining boundaries in relation to their own mental health and well-being. For example, the study findings revealed that some of the caregivers had experienced high levels of stress and mental distress at some point of their career as a result of working with suicidal and sexually abused HIV positive individuals. Other researchers have found similar findings that high occupational stress, depression, burnout, unresolved grief manifest themselves more sharply and more strongly in the HIV/AIDS field than in any other fields of care (Bellani et al., 1996). In addition, Carmack (1997) found that caregivers in formal settings that placed and maintained boundaries, were able to better monitor and balance their work related activities with the individuals in their care, and thus recognized the importance of practicing self-care.

The findings showed that self-care was one of the important aspects of caregiving in every caregiving settings whether it was formal or informal. Most of the caregivers acknowledged the importance of self-care and engaged in some sort of self-care activities such as debriefing, sharing and discussing work related issues with coworkers and managers, and spending time with family and friends. Smith's study (2007) also emphasized the importance of self-care for those caregivers and clinicians who worked closely with individuals of HIV/AIDS. Smith (2007) indicated there was a high risk of compassion fatigue, burnout and stress for clinicians and social workers working with HIV/AIDS clients; therefore, they needed to look into self-care carefully and practice a number of different strategies to remain healthy.

However, some of the caregivers in community support sector pointed out that at times self-care related activities were not enough and that they needed some sort of spiritual support to detach their emotions when occupational stress was rising. Detaching personal emotions was one of the key elements in the caregiving field that other scholars and researchers have found out to be effective and have suggested to be employed in caregiving settings. For example, Carmack (1997) suggested that detaching personal emotions and maintaining balance between work and self-care could help caregivers to stay focused and not become overwhelmed by another person's needs or stress.

The findings revealed that early leaving the field of caregiving and staff turnover was one of the issues that most of care provider organizations were facing. One of the reasons for high staff turnover was that there was occupational stress and burnout in the HIV/AIDS caregiving settings which was affecting the well-being of the caregivers and specially those who were new in this field. On the other hand, at the organizational level, replacing caregivers and providing job related training was costly and all organizations did not have the resources to provide adequate training and education for new comers. Aiken et al. (2002) have indicated that burnout poses serious concerns as it increases employees' turnover and decreases the quality of care provided to patient. Other scholars' research showed that caregivers in the HIV/AIDS field were experiencing high level of stress, depression, burnout which resulted in high staff turnover and change of career (Bellaniet al., 1996).

The study findings suggested that establishing and maintaining professional boundaries were very challenging for all caregivers. Though caregivers had learned boundaries in their practice, sticking to them was hard at times especially when they were caring for some individuals with lots of vulnerability and health issues. Also, maintaining boundaries in small cities was hard for these caregivers as they would encounter clients on social events held at parks

and public places such as small Christmas parties, live shows, and concerts. These caregivers were coming across with the individuals in their care and they were approaching their caregivers and trying to engage and connect on a closer level or disclose more personal information to them. This finding supports existing studies and research that have also acknowledged the fact that boundaries are hard to establish and maintain, but they can be learned through experience over time as well (Arnold, 1990; Carmack, 1997).

When discussing the experience of all caregivers in the study and comparing them in relation to how much the people at their care tried to get detailed and personal information about their personal lives, the findings were similar. All of the study participants working with people living with HIV/AIDS had experienced similar situations. Whether they were physicians, outreach workers, frontline works or social workers, they all were asked about their personal and private life by people in their care. Furthermore, when these caregivers tried to get detailed information about the personal sex life of the people at their care, the care recipients also thought that it was ok for them to ask the same questions from their caregivers. All of these caregivers and workers stated that boundary did not play much of a role when it came to personal and private life of them as boundary could not prohibit the care receivers from asking personal questions.

It is important to acknowledge the limitations of this study. One of the limitations of this study was that the researcher did not participate in the primary research study (Social Support, Informal Caregiving and HIV/AIDS: A community-Based Study) conducted by Mignone et al. (2011).Also, the researcher for this study used secondary data set which placed limitation on the extent and depth of the data that could otherwise could be collected through a primary data set.

In terms of recommendations, since caregivers are in charge of people in different settings and are expected to respond to many needs of people in their care, it is important for

them to adapt and practice different methods of self-care. Therefore, it is necessary to provide a relaxing and friendly working environment for formal caregivers who are working on a regular basis with stigmatized and low income people living with HIV/AIDS in order to prevent and reduce stress and burnout and increase positive energy and productivity. Adding recreational activities to boost mood and mental health such as yoga and meditation, dancing, and stretching classes are highly recommended. There is very limited research on how caregivers in HIV/AIDS sector perceive their relationships with marginalized people living with HIV/AIDS, so further research is recommended in this area.

Finally, the inherent stigma of HIV/AIDS in the society carries over to the caregiving field as well; and it might express itself as an ethical issue when some caregivers do not feel comfortable working with HIV positive individuals. Consequently, specific training should be provided for caregivers working with this population to raise awareness about the disease, to cope with the stigma and possibly mitigate caregiver's own biases prior to working with this marginalized group of people.

Figure 1

Six steps of thematic analysis and rigour by Braun and Clarke (2006)

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