ASSOCIATION BETWEEN STIGMA, PSYCHOLOGICAL DISTRESS, AND QUALITY OF LIFE AMONG PEOPLE LIVING WITH HIV IN FEDERAL TERRITORY OF KUALA LUMPUR

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ASSOCIATION BETWEEN STIGMA, PSYCHOLOGICAL DISTRESS, AND QUALITY OF LIFE AMONG PEOPLE LIVING WITH HIV IN FEDERAL TERRITORY OF KUALA LUMPUR

ABSTRACT

Quality of life is an important component in the evaluation of the well-being of PLHIV. However, HIV stigma and psychological distress (depression, anxiety and stress) continue to be a barrier to obtain a good quality of life among PLHIV globally. This study assesses the level of QOL, stigma and psychological distress among PLHIV in Kuala Lumpur by determining the association between QOL, stigma and psychological distress. A cross-sectional study was conducted, involving 305 PLHIV attendees of the infectious disease clinic in a teaching hospital, primary health clinic and three Community-Based Organisations (CBOs). The sampled respondents completed face to face interviews using a standardised structured questionnaire on quality of life scale (WHO-QOL HIV BREF), Depression, Anxiety and Stress Scale (DASS) and HIV Stigma Scale. Total quality of life of respondents in this study was in the low to moderate range (mean 93.7; SD 15.6) and was significantly impaired by the social relationship domain (mean score 12.9; SD 3.2) followed by the spirituality domain (mean score 12.4; SD 2.4). On the other hand, psychological domain (mean score 13.8; SD 2.7) and ability to perform daily activities (physical domain) was not affected by the illness (mean score 13.7; SD 3.08). The mean total QOL was significantly higher among respondents from the teaching hospital and primary health clinic compared to CBOs respondents, which could be due to the availability of HAART treatment. The overall stigma experienced by PLHIV in this study was moderate (mean score 100.4; SD 17.3). Stigma was highest in the disclosure domain, where difficulty to disclose HIV serostatus may be influenced by the cultural and religious belief of PLHIV. It is interesting to note that PLHIV in this study least experienced negative self-image stigma (shame and guilt). This may reflect them having a high perceived stigma but low internalised stigma, which suggests they did not experience the negative consequences of stigma. Stigma was associated with higher odds of depression (Adjusted OR 1.05, 95% CI 1.02-1.07), anxiety (Adjusted OR 1.04, 95% CI 1.02-1.06) and stress (Adjusted OR 1.03, 95% CI 1.00-1.06) and was negatively correlated with all QOL domains. This study also found that psychological manifestation was prevalent among PLHIV with 48.7% of respondents having depression, 58.4% anxiety and 30.5% stress. Depression, anxiety and stress were negatively associated with all QOL domains and associated with lower odds of good quality of life (Adjusted OR 0.92, 95% CI 0.89-0.94) for depression, (Adjusted OR 0.94, 95% CI 0.92-0.96) for anxiety and (Adjusted OR 0.92, 95% CI 0.90-0.95) for stress. In conclusion, these findings confirm that stigma and psychological distress make a distinctive, significant contribution to overall QOL. Therefore, focus on efforts to diagnose and treat depression, anxiety and stress while enhancing spiritual and psychological support are strategies to improve QOL among PLHIV. Finally, it is important to address disclosure stigma among PLHIV by having active interaction between PLHIV with healthcare workers, family members, employers and the society to empower and provide safe disclosure among PLHIV.

Keywords: PLHIV, QOL, depression, anxiety, stress, stigma, HAART

HUBUNGAN ANTARA STIGMA, TEKANAN PSIKOLOGI, DAN KUALITI KEHIDUPAN DIKALANGAN ORANG HIDUP DENGAN HIV/AIDS (ODHA) DI WILAYAH PERSEKUTUAN KUALA LUMPUR

ABSTRAK

Tahap kualiti kehidupan adalah komponen penting dalam penilaian kesejahteraan kehidupan orang hidup dengan HIV/AIDS (ODHA). Walau bagaimanapun, stigma dan tekanan psikologi (kemurungan, keresahan dan stres) merupakan salah satu faktor penghalang memperolehi tahap kualiti hidup yang baik di kalangan ODHA di seluruh dunia. Tujuan kajian ini adalah menilai tahap kualiti kehidupan, stigma dan tekanan psikologi di kalangan PLHIV di W.P Kuala Lumpur. Kajian ini juga bertujuan untuk menentukan hubungan antara kualiti kehidupan, stigma dan tekanan psikologi. Kajian rentas telah dijalankan, melibatkan 305 orang responden ODHA daripada klinik penyakit berjangkit di hospital universiti, klinik kesihatan primer dan tiga organisasi berasaskan komuniti (CBO). Responden menyelesaikan temuduga bersemuka dengan menggunakan soal selidik berstruktur yang standard pada skala kualiti hidup (WHO-QOL HIV BREF), skala depresi, keresahan dan stres (DASS) dan skala stigma HIV. Tahap kualiti hidup responden dalam kajian ini didapati berada dalam julat rendah ke sederhana (min 93.7; SD 15.6) dan rendah pada domain hubungan sosial (min 12.9; SD 3.2) diikuti oleh domain kerohanian (min 12.4; SD 2.4). Disamping itu, domain psikologi (min 13.8; SD 2.7) dan keupayaan untuk melakukan aktiviti harian (domain fizikal) tidak terjejas oleh penyakit ini (min 13.7; SD 3.08). Keseluruhan jumlah tahap kualiti kehidupan adalah jauh lebih tinggi di kalangan responden dari hospital universiti dan klinik kesihatan primer berbanding dengan responden dari organisasi berasaskan komuniti (CBO) yang mungkin disumbangkan oleh adanya rawatan anti virus HIV (ART). Stigma keseluruhan yang dialami oleh PLHIV dalam kajian ini dianggap sederhana (min skor 100.4; SD = 17.3).

Stigma adalah tertinggi dalam domain pendedahan di mana kesukaran untuk mendedahkan serostatus HIV mungkin dipengaruhi oleh nilai kepercayaan, budaya dan agama dikalangan ODHA. Stigma imej negatif (rasa malu dan rasa bersalah) adalah bentuk stigma yang paling kurang dialami oleh ODHA dalam kajian ini. Ini mungkin mencerminkan bahawa ODHA mempunyai stigma yang tinggi namun tiada stigma dalaman yang menunjukkan bahawa mereka tidak mengalami akibat negatif disebabkan oleh stigma. Stigma juga dikaitkan dengan kebarangkalian kemurungan yang lebih tinggi (Adjusted OR 1.05, 95% CI 1.02-1.07), keresahan (Adjusted OR 1.04, 95% CI 1.02-1.06) dan stres (Adjusted OR 1.03, 95% CI 1.00-1.06) dan berkadar negatif dengan semua domain kualiti kehidupan. Kajian ini juga menunjukkan manifestasi psikologi yang lazim di kalangan ODHA dimana 48.7% responden mengalami kemurungan, 58.4% keresahan dan stres 30.5%. Kemurungan, keresahan dan stres juga dikaitkan secara negatif dengan semua domain kualiti kehidupan dan kebarangkalian tahap kualiti kehidupan yang rendah (Adjusted OR 0.92, 95% CI 0.89-0.94) bagi kemurungan, (Adjusted OR 0.94, 95% CI 0.92-0.96) keresahan dan (Adjusted OR 0.92, 95% CI 0.90-0.95) stres. Secara kesimpulan, hasil kajian ini mengesahkan bahawa stigma dan tahap tekanan psikologi adalah penting bagi menentukan tahap kualiti kehidupan ODHA. Oleh itu, tumpuan terhadap usaha untuk mendiagnosa dan merawat kemurungan, keresahan dan stres disamping meningkatkan sokongan rohani dan psikologi adalah strategi penting bagi memperbaiki tahap kualiti kehidupan ODHA. Disamping itu, adalah penting menangani stigma pendedahan status jangkitan di kalangan ODHA melalui interaksi aktif antara ODHA dengan anggota kesihatan, ahli keluarga, majikan dan masyarakat umum agar dapat memberi ruang yang selamat bagi pendedahan status dikalangan ODHA.

Kata kunci: orang hidup dengan HIV/AIDS (ODHA), kemurungan, keresahan, stress, tekanan psikologi, stigma.

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LIST OF SYMBOLS AND ABREVIATIONS

ART	:	Anti-Retroviral Therapy
ARV	:	Anti-Retroviral
CBO	:	Community-based Organisation
DIC	:	Drop-in Centre
FSW	:	Female Sex Worker
HAART	:	Highly Active Anti-Retroviral Therapy
HIV	:	Human Immunodeficiency Virus
MSM	:	Summary of Diabetes Self-Care Activities
IBBS	;	Integrated Bio-Behavioural Survey
MOH	:	Ministry of Health
NATCA	:	National Advisory and Technical Committee on AIDS
NGO	:	Non-Governmental Organization
PLHIV	:	People living with HIV
PWID	:	People who inject drug
SW	:	Sex worker
STI	:	Sexually Transmitted Infection
TG	:	Transgender
WHO	:	World Health Organization

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CHAPTER 1: INTRODUCTION

1.1 Chapter Overview

This chapter begins by defining Human Immunodeficiency Virus (HIV), followed by an HIV epidemic overview and the burden of HIV in Malaysia. The chapter ends by stating the problems, objectives, research questions and public health significance of the study.

1.2 HIV pandemic

The Human Immunodeficiency Virus (HIV) caused a pandemic of infectious disease in the 1980s. In 1985, HIV was a full-scale pandemic globally with a huge number of cases in each continent. Globally, more than 38 million people were living with HIV (PLHIV), and in 2005, more than 2 million people have died from AIDS (UNAIDS, 2006). It is estimated that every day, more than 7000 people are newly infected with HIV (UNAIDS, 2010). The majority (70%) of the total global number of PLHIV are from Sub-Saharan Africa, namely from Nigeria and South Africa. This is followed by the Asian and Pacific Region where China, India, Indonesia, Myanmar, Thailand and Vietnam account for more than 90% of PLHIV in the region. In 2013, India had the highest number of PLHIV, with more than 2 million PLHIV (UNAIDS, 2014).

Globally, there is a declining trend of newly infected people with HIV following the global commitment to the Millennium Development Goal (MDG) and Declaration of Commitment on HIV/AIDS in 2001. This resulted in more than 30% decline of new HIV infections between 2001 to 2013 with a reduction of new HIV cases from 3.4 million to 2.1 million. There was a 75% decline in new HIV infections in ten countries and a 50% decline in 27 countries (UNAIDS, 2014).

1.3 An Overview of The Malaysia HIV Epidemic

Malaysia has recorded a reduction of new cases in line with the declining global trend. Cases declined by almost 50% from 28.4 per 100,000 people to 11.7 cases per 100,000 people from the years 2002 to 2014. The Malaysia cumulative HIV cases reported by the national surveillance system in the year 2014 was 105,189 cases, 21,384 AIDS cases and 17,096 deaths related to HIV/AIDS. Figure 1 illustrates the number of reported HIV cases and AIDS-related deaths since the first reported case of HIV in 1986.

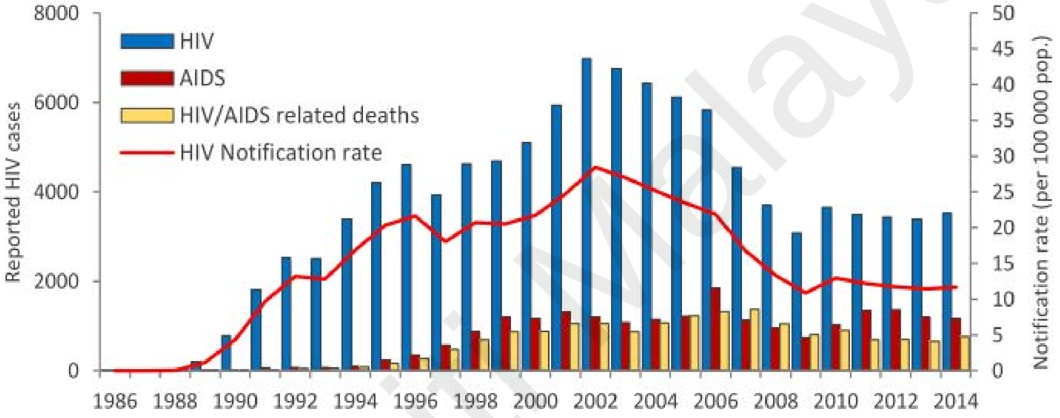


Figure 1: HIV, AIDS and AIDS-related death cases, Malaysia 1986-2014.
Source: National Strategic Plan Ending AIDS 2016-2030, 2015

According to World Health Organisation (WHO) classification, Malaysia has a concentrated HIV epidemic with prevalence less than <1% in the general population and persistent prevalence of more than >5% among key populations (KPs) like people who inject drugs (PWID), men sex with men (MSM) and transgender (TG) (HIV/STI Section Ministry of Health Malaysia, 2012).

At the beginning of the HIV epidemic, the key driving factor was people who injected drugs with a ratio of people who inject drug (PWID) versus sexual transmission of 12.2. However, in 1994, the mode of transmission shifted to sexually risky behaviour compared to PWID with the ratio declining to 0.2 in 2014 (HIV/STI Section Ministry of Health

Malaysia, 2016) (Figure 2). HIV infection among women accounts for less than 10% of cumulative HIV cases and men represent the majority (90.8%). Women acquired HIV infections mostly through heterosexual transmission (70%), and only 20% is due to injecting drug risk behaviour (HIV/STI Section Ministry of Health Malaysia, 2012). A snapshot of the HIV epidemic in Malaysia is depicted in Figure 3.

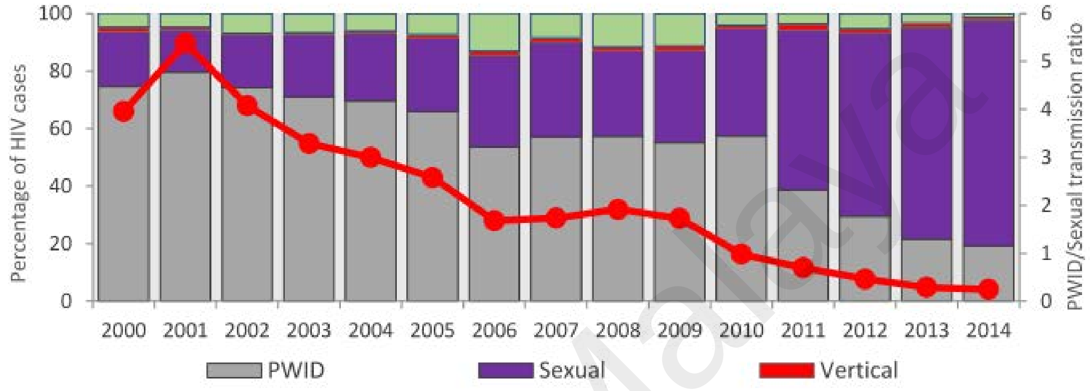


Figure 2: Percentage of HIV cases by mode of transmission and PWID / sexual transmission ratio, Malaysia 2000-2014
Reference: Global AIDS Response Progress Report Malaysia, 2015

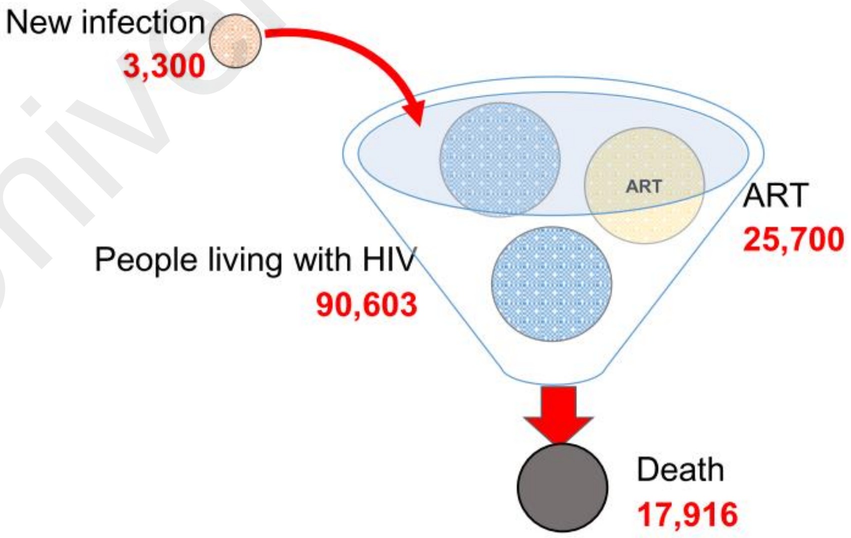


Figure 3: HIV epidemic snapshot in Malaysia 2015
Reference: Global Aids Response Progress Report Malaysia, 2016

The geographical distribution of HIV cases in Malaysia showed quite a distinct transmission trend between states. HIV transmission in the Eastern region (Terengganu, Kelantan and Pahang) is mainly contributed by PWID, while in northern (Perlis, Perak, Penang and Kedah) and southern regions (Melaka, Johor and Negeri Sembilan), HIV transmission have shifted from PWID to sexually risky behaviour. The central region (Selangor and Kuala Lumpur) was PWID driven and has become sexually driven, whereas Sarawak and Sabah are predominantly sexually driven (HIV/STI Section Ministry of Health Malaysia, 2016). Five states in Peninsular Malaysia (Kelantan, Pahang, Johor, Terengganu and Selangor) account for 62% of total PLHIV cases in Malaysia (Figure 4). In the year 2015, 7.5% of PLHIV were reported in the Federal Territory Kuala Lumpur.

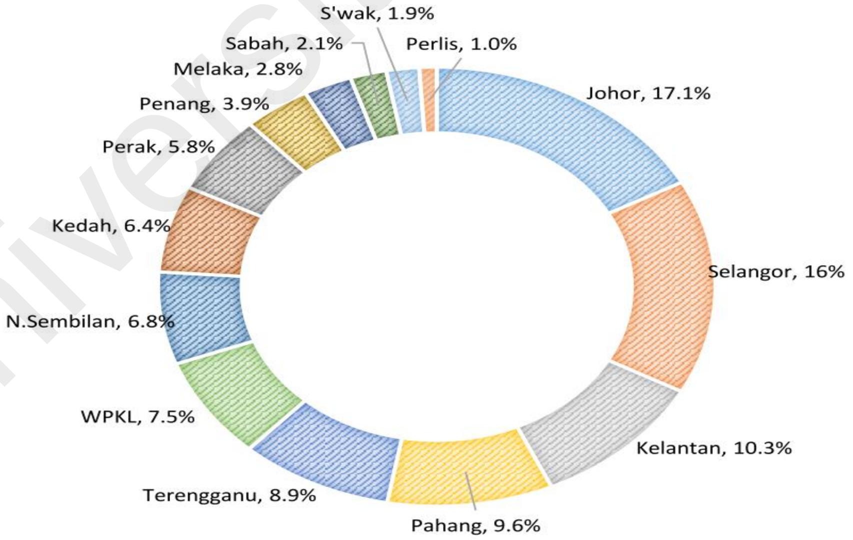


Figure 4: Distribution of PLHIV according to states in Malaysia 2015
Source: Global Aids Response Progress Report Malaysia, 2016

Figure 5 showed the proportion of new HIV cases reported according to the age group from the years 1990 to 2015. There has been an increasing proportion of HIV cases among those aged 13 to 29 years from 2010, which was between 30% to about 34% in 2014. The proportion of HIV cases for those aged 13 years or less has been kept constant to around 1%.

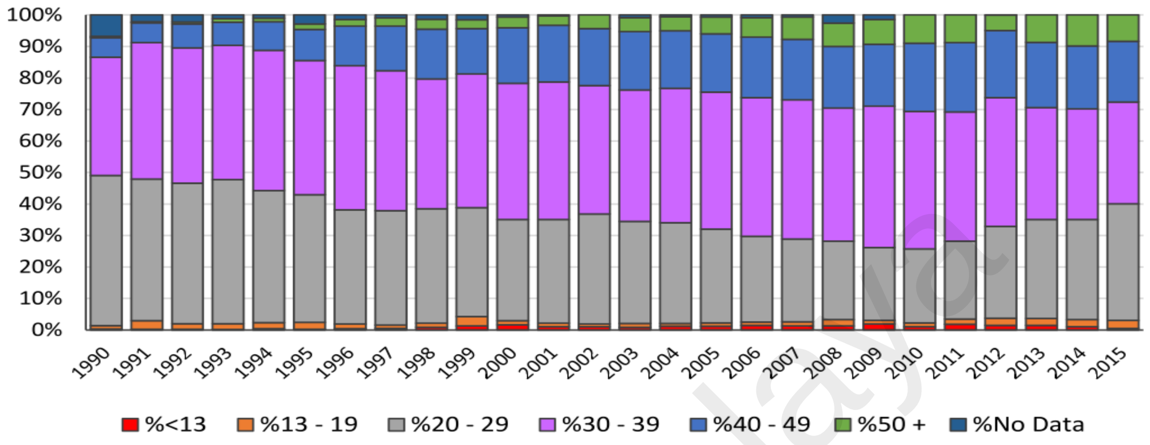


Figure 5: New HIV cases reported by age group 2000-2015
Reference: Global AIDS Response Progress Report Malaysia, 2016

The majority (89%) of HIV cases in Malaysia were males (Figure 5). However, there is a shift towards increasing rates of HIV infection among females with the male/female ratio declining from 9.6 in 2000 to 5.5 in 2015 (HIV/STI Section Ministry of Health Malaysia, 2016).

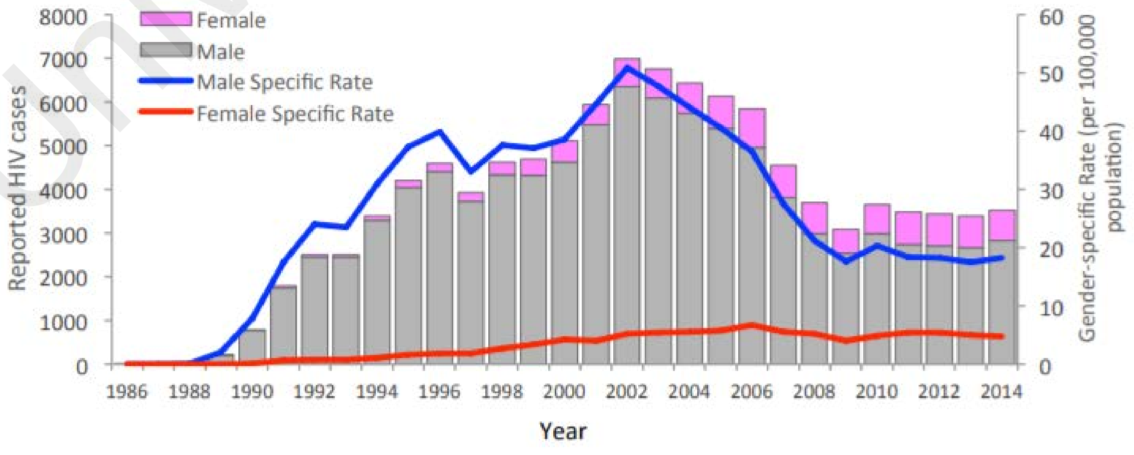


Figure 6: Male and female specific HIV prevalence, Malaysia 1986-2014
Source: Global AIDS Response Progress Report Malaysia, 2015

1.4 Key Populations

The term ‘key populations’ or ‘most at-risk populations’ (MARPs) refer to vulnerable and high-risk groups. These populations are at high risk of being infected with HIV or affected by HIV. They are also described as difficult to reach populations, vulnerable to abuse, discrimination, and stigma. It describes individuals risk of HIV exposure (e.g. due to unprotected sex, lack of access to sterile injecting equipment among PWID) (UNAIDS, 2015). In the Malaysian context, four key populations with high-risk of getting HIV infections include people who inject drugs (PWID), men who have sex with men (MSM), female sex worker (FSW) and transgender (TG) (HIV/STI Section Ministry of Health Malaysia, 2016).

1.4.1 People Who Inject Drugs (PWID)

PWID drove the HIV epidemic in Malaysia at the beginning of the epidemic, with more than 70% of new reported HIV cases. The prevalence started to decline in 2004 to only 19% of new cases reported in 2014. A similar pattern was demonstrated in the Integrated Bio-Behavioural Survey (IBBS), where the prevalence of PWID infected with HIV declined from 22% in 2009 to 16% in 2014. The decline in prevalence among PWID resulted from the harm reduction programme where the use of clean needles for injection became a widespread practice. Spouses of PWID are potential “hidden population” vulnerable to HIV due to heterosexual transmission (HIV/STI Section Ministry of Health Malaysia, 2016).

1.4.2 Sex Workers

According to the Positive Malaysian Treatment Access & Advocacy Group (2012), sex work activities exist underground due to the stigma and discrimination within the society and prohibitive laws of practising sex work in Malaysia. This leads to gross underreporting of this group of the population since they will not identify themselves and come forward for HIV screening. Sex work activities can be venue-based or non-venue-based sex work with a variety of places including hotels, massage parlour, karaoke bar, streets and even homes. The Integrated Bio-Behavioural Survey (IBBS) has been implemented twice in Malaysia covering 845 commercial sex worker (CSW) in the years 2003 and 2004 in five study sites, namely Kuala Lumpur, Johor, Sarawak, Pulau Pinang, and Kelantan. The IBBS study showed there was an increase in HIV prevalence among female sex workers from above 5% to 10.5% in 2009 (UNAIDS, 2010). IBBS showed only 60% of respondents use a condom, which indicates that clients of sex workers were at risk of becoming infected with HIV and can further spread the transmission through sexual intercourse (UNAIDS, 2005). The IBBS study in 2009 showed the highest prevalence of female sex workers of 10.5% compared to 4.2% in 2012 and 7.3% in 2014 (HIV/STI Section Ministry of Health Malaysia, 2015a).

1.4.3 Men Who Have Sex with Men (MSM)

According to the HIV/STI Section Ministry of Health Malaysia (2015), men who have sex with men are defined as men who engage in anal sex and is often related to having multiple sexual partners. Very limited study has been done on this group in Malaysia. Therefore, very little is known about them. There were 173,000 estimated MSM in Malaysia (www.aidsdatahub.org, 2011). In 2009, a study was done by Kanter et al. (2011) on the MSM venues in the Federal Territory Kuala Lumpur among 517 respondents showed 3.9% prevalence of HIV among this population. The majority of respondents were Malays (47%), followed by Chinese (43.7%). Respondents with unprotected sex with a casual partner and receptive partners of MSM were three times more likely to be

HIV positive. It is also reported that having group sex activities increased the risk of HIV infection fourfold.

1.4.4 Transgender

Transgendered persons, also known as transsexuals, are usually labelled as sexual deviants. The IBBS survey conducted in 2009 among the transgender community showed an HIV prevalence of 9.3%. It was reported that four out of five transgenders were selling sex and 94% of respondents practice condom use with a client during the last sexual encounter. However, the practice of not using a condom with non-paying sexual partners like a boyfriend or regular client was between 4.8% to 5.6% (HIV/STI Section Ministry of Health Malaysia, 2012).

1.5 The Global and National Response towards the AIDS Epidemic

Globally, initiatives for the AIDS epidemic are moving towards ending AIDS as a public health threat. This can be achieved by reducing 90% of new HIV infections and AIDS-related deaths by the year 2030 compared to the baseline in the year 2010 (HIV/STI Section Ministry of Health Malaysia, 2015). With the invention of ARV, the lifespan of PLHIV had dramatically extended longer and has been effectively prevented HIV transmission when the viral load is kept low. The 90-90-90 targets were set in which by the year 2020, 90% of PLHIV know their HIV status, 90% of people who know their status receive treatment and 90% of people on HIV treatment have successfully suppressed their viral load. The target is to reduce the number of adults with HIV infection from 2.1 million in 2010 to fewer than 500 000 in the year 2020 to fewer than 200 000 in the year 2030. This would mark the end of the AIDS epidemic as a public health threat (HIV/STI Section Ministry of Health Malaysia, 2015).

In line with the global target, the Malaysian government, through the National Strategic Plan for Ending AIDS (NSPEA) 2016-2030, agrees on the vision of ending AIDS by 2030 by having 90% reduction of new HIV cases from the baseline in the year 2010. The NSPEA is targeting zero new infections, zero discrimination and zero AIDS-related deaths. There were nine listed responses by the government towards the AIDS epidemic as described in the NSPEA 2016-2030 as details in the following sections.

1.5.1 National Political Commitment

A successful response to the HIV epidemic in Malaysia was the strong national political commitment and leadership at the highest administrative level. The National AIDS Taskforce was formed in 1985, responsible for formulating policies strategies and chaired by the Director General of Health. The National AIDS Taskforce assumed the role of coordinator of the national HIV/AIDS prevention and control programme. In 1992, the Inter-Ministerial Committee on HIV/AIDS (CCA) was established to coordinate inter-ministerial collaboration between the Ministry of Health with other government agencies like the Ministry of Education, Ministry of Home Affairs, Ministry of Women, Family and Community Development, Malaysia Department of Islamic Development (JAKIM) and working together with Non-Governmental Organisations (NGOs) in response to the epidemic. Later, in 2009, the CCA was replaced by the National Coordinating Committee on AIDS Intervention (NCCAI) chaired by the Minister of Health. Members of this committee include the General Secretaries of 16 ministries and government agencies listed in the NSPEA and civil society representatives, which includes the Malaysian AIDS Council (MAC). The NCCAI is supported by The National Advisory and Technical Committee on AIDS (NATCA), which is the highest level advisory body in the country (HIV/STI Section Ministry of Health Malaysia, 2012).

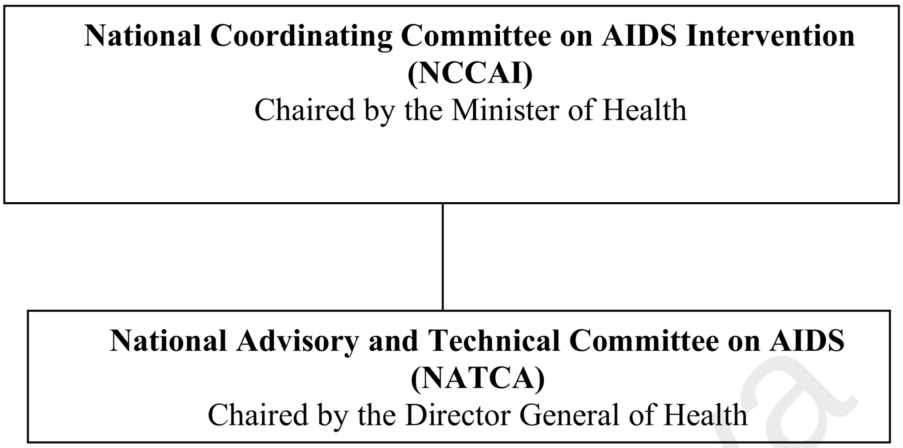


Figure 7: Malaysia National HIV and AIDS Policy Framework
Reference: National Strategic Plan (NSP) on HIV/AIDS 2006 -2010

Malaysia's responses to HIV were guided by a series of national plans beginning with The National Plan of Action 1988 and the Reviewed Plan of Action 1998, followed by the National Strategic Plan 2006-2010, National Strategic Plan 2011-2015 and ongoing National Strategic Plan for Ending AIDS 2016-2030 (HIV/STI section the Ministry of Health Malaysia, 2015).

1.5.2 Key Populations Involvement with Civil Society

Acknowledging the importance of civil society engagement, the government has allocated a special budget yearly to the Malaysian AIDS Council (MAC) which plays a role as an umbrella organisation for Malaysian NGOs, including the community-based organisations and civil society working on HIV-AIDS. It has benefitted more than 30 NGOs with more than RM80 million funding yearly. PLHIV and key populations (PWID, MSM, SW, transgender and heterosexuals) were engaged in decision-making through their active participation in NCCAI and CCM at the national level.

1.5.3 Treatment and Care

Anti-Retrovirals (ARV) cannot eradicate HIV from the human body nor cure HIV infection. Therefore, the goal and benefits of anti-retroviral therapy (ART) includes (Malaysian Society for HIV Medicine - MASHM, 2017):

a) Reduce mortality and morbidity related to HIV
b) To improve the quality of life (QOL) of PLHIV
c) To increase the lifespan of PLHIV
d) To restore and preserve the immunologic function
e) To suppress viral load
f) To reduce complications associated with HIV and AIDS
g) To prevent HIV transmission to sexual partner and from mother to child through pregnancy
h) To prevent the development of HIV drug resistance

The Malaysian government is providing free first-line ARV treatment for eligible PLHIV, which includes the incarcerated populations and inmates in drug rehabilitation centres (HIV/STI Section Ministry of Health Malaysia, 2015a). Additionally, the government heavily subsidises the second line regime ARV (Malaysian Society for HIV Medicine, 2017). In 2010, the treatment policy of ART was improved to increase the number of PLHIV on treatment by shifting the CD4 cut-off level from 200 to 350 cells/µl for initiation of ART. Later, in the year 2014, the government introduced treatment for serodiscordant couples for the prevention of HIV transmission (Malaysian Society for HIV Medicine, 2014)

ART is available in all government hospitals and more than 200 health clinics nationwide. It is also available through referral to facilities which provide ART. HIV services are made accessible, affordable and acceptable to the entire community, especially key populations by integrating HIV management in the Primary Healthcare System. Since its implementation, there were increasing numbers of cases managed at health clinics from 3,200 cases in 2001 to 5,800 cases in 2002 with 250 clinics throughout the country (HIV/STI section Ministry of Health Malaysia, 2015). Figure 8 shows the HIV testing procedure flowchart and follow-up at the primary health clinics.

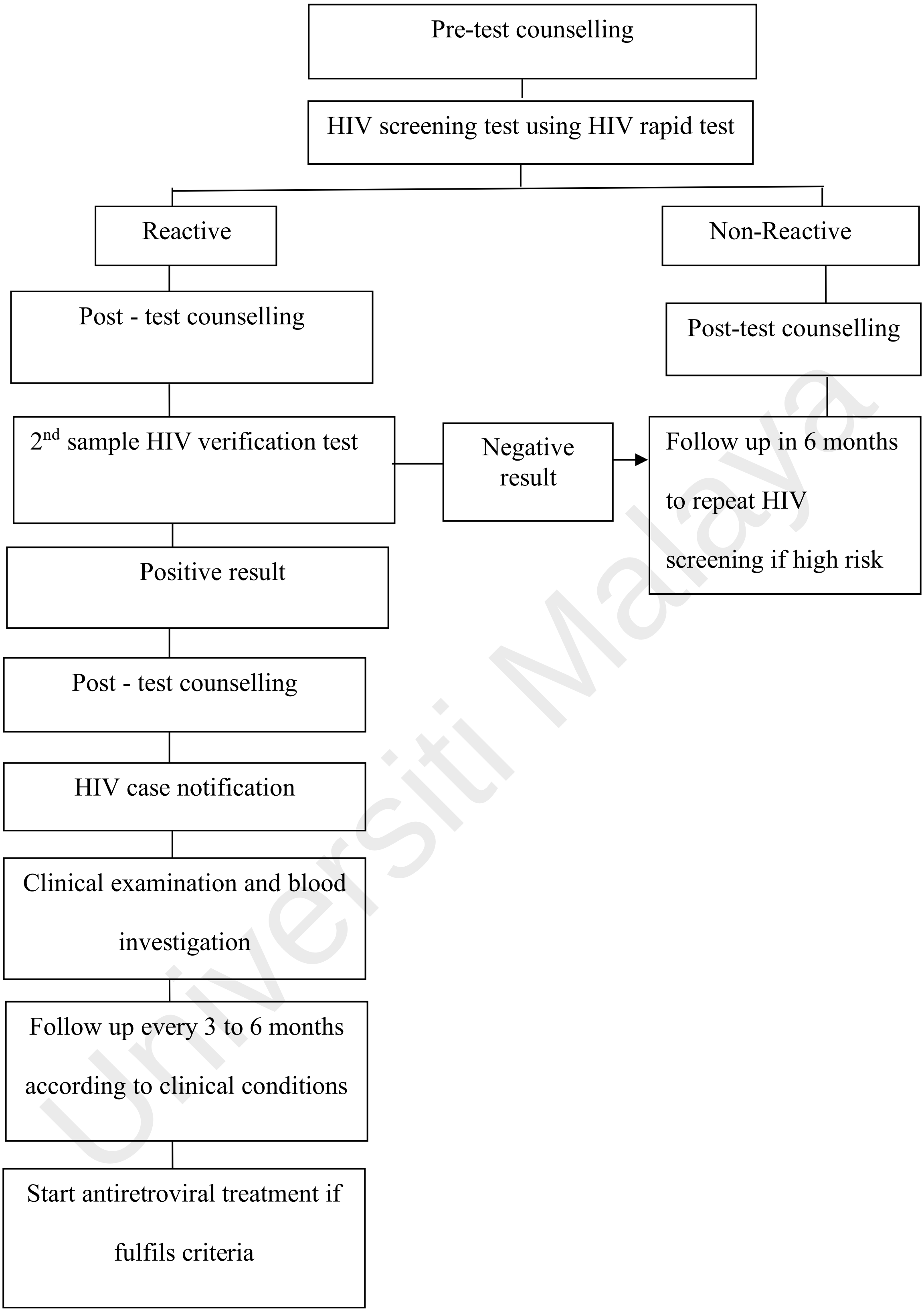


Figure 8: Flowchart of HIV testing and follow up in the primary care setting
Reference: Tanglin Health Clinic, FT Kuala Lumpur

1.5.4 Prevention Through Harm Reduction

In 2005, the government piloted two harm reduction programmes, which are the Opiate Substitution Therapy (OST) and Needle and Syringe Exchange Programme (NSEP). Both programmes were implemented in partnership with NGOs, CBOs, and private health practitioners involving inmates of the prisons and at the National Anti-Drug Agency (NADA) centres. By the year 2007, the number of NSEP sites increased from three pilot sites to six sites, and in 2015 there were 728 NSEP sites. The NGOs provided the majority of NSEP sites with 540 sites and 152 sites in the government clinics. The number of OST outlets has increased from three pilot sites in 2006 to 838 outlets in 2015. The OST programme has reached more than 70,000 drug users with more than 17,000 people benefiting from Methadone while the NSEP has accessed more than 11,000 drug users in 2009 (Anne Bergenstrom 2009). The IBBS 2014 indicated that more than 95% of PWID had used clean needles. The harm reduction programme in Malaysia has been acknowledged as successfully reducing new HIV infections worldwide.

1.5.5 Prevention of Sexual Transmission

The IBBS conducted in 2014 indicated an unsatisfactory understanding of the prevention of sexual transmission of HIV among key populations. Therefore, a strategy to address the rise of sexual transmission of HIV should include educating and delivering sexual reproductive health services to the key populations (SW, MSM and transgender) by engaging civil society. The prevention of sexually transmitted infection (STI) activities shall include HIV testing, access to free condoms, education, outreach and peer educator to promote behaviour change communication.

1.5.6 Prevention of Mother to Child Transmission (PMTCT)

The prevention of mother to child HIV transmission among antenatal mothers' programme was introduced nationwide in 1998. In this programme, HIV positive mothers were started on ART, and HIV-exposed infants were given prophylaxis ART. Since 2012, infants born from positive mothers were given free replacement feeding for two years followed by an HIV polymerase chain reaction (PCR) test. Since implementation, 349 pregnant women received ARV prophylaxis with more than 98% of mothers delivering HIV negative babies whereby infections due to mother to child transmission were prevented successfully. The HIV transmission rate when there has was no intervention reduced from 30% to 40% to 1.3%.

1.5.7 Stigma and Discrimination

The IBBS findings in 2014 indicated that around 60% of PLHIV experienced self-stigma and up to 50% of PLHIV experienced verbal abuse related to their HIV serostatus, while 20% had experienced harassment, discrimination, and physical violence as a result of their HIV serostatus (HIV/STI Section Ministry of Health Malaysia, 2015). The government role in the prevention, provision of care and support programmes with key populations are important strategies to reduce stigma and discrimination. A strategy that has helped reduce stigma and discrimination among PLHIV was the active involvement of religious leaders and religious bodies under the Department of Islamic Development (JAKIM) in providing financial support and welfare guidance to shelter home for Muslim PLHIV. Another example was the establishment of the Treatment and Adherence Support Programme (TAPS). TAPS were conducted by partner organisations and funded by the government to provide PLHIV information and education on antiretroviral treatment, adherence and healthy lifestyles. The support programme also provides hospital clients with outreach services for psychological and emotional support. This includes adherence to ART and to ensure the continuum of care upon being discharged from the hospital. In 2014, ten partner organisation conducted TAPS in more than 20 treatment centres and 16 shelter homes, reaching nearly 5000 PLHIV clients and those affected by HIV, which includes their family and friends. Shelter homes provide services which include basic nursing care, medical referrals, psychological support, palliative care and teaching life skills.

1.6 Malaysia Priorities for Ending AIDS Strategies

The National Strategic Plan for Ending AIDS 2016-2030 has prioritised activities to maximise the impact of responses to generate the best returns. Four priority areas have been identified by the Malaysia Ministry of Health as follows:

1.6.1 Priority 1: HIV Testing and Treatment

Effective treatment prevents death and transmission of HIV, and it will require HIV testing to diagnose HIV and deliver treatment to those eligible. It is stipulated that the HIV transmission rate will drop by 1% at the population level for every increase in 10% of PLHIV put on treatment (HIV/STI section Ministry of Health Malaysia, 2015). As such, Malaysia's strategy towards ending AIDS by the year 2030 is by achieving the 95-95-95 target. The target aims to test 95% of key populations for HIV and know their results, to place 95% of people diagnosed with HIV on ARV treatment and to achieve 95% HIV suppression of people on ART. In the 2016-2020 NSP, Malaysia has committed to fast-tracking the response to achieve 90% of the above targets by the year 2020. To reach the target, it will intensify HIV testing among the high-risk group, increased fourfold the number of PLHIV on treatment by treating all PLHIV irrespective of the CD4 count.

1.6.2 Priority 2: Harm Reduction

More than 80% of the estimated 170,000 PWID population in Malaysia have been enrolled in the harm reduction programme. However, the proportion of PWID initiated with ART is still very low due to low social support and poor adherence to treatment among PWID. One alternative to improve treatment coverage among PWID is to enrol them in the Opiate Substitution Therapy (methadone maintenance therapy) and provide better social support.

1.6.3 Priority 3: Sexual Transmission

A special taskforce has been formed in response to the increasing sexual transmission trends. In order to fast track and eventually end AIDS, the sexual transmission prevention programmes need to cover at least 80% of key populations. This can be done by developing effective messages to reverse HIV transmission through unprotected sex confined to the key populations by escalating condom use.

1.6.4 Priority 4: HIV Stigma and Discrimination

Addressing stigma and discrimination is an important strategy to end AIDS. This can be achieved by having multi-sectoral collaboration between government agencies, civil society and law enforcement authorities to address stigma and discrimination issues faced by key populations. Strategies to reduce stigma among PLHIV include increasing the availability and accessibility to healthcare, to strengthen PLHIV support programmes, to increase social, religious, mental and spiritual support, and to address the physical and economic needs of PLHIV.

The collective strategy by the government to end AIDS as listed above will enable PLHIV to have a good quality of life. It will also reduce the social and economic impact resulting from HIV on the individual, family members and society as detailed in the goal of the National Strategic Plan on HIV and AIDS.

Da Silva, Bunn, Bertoni, Neves, & Traebert (2013) described quality of life as "the respondent perception assessed according to his or her position in life in the context of the culture and value systems in which the individuals live and in relation to his or her goals, expectations, standards and concerns". Quality of life (QOL) has become an important assessment to understand how PLHIV live. The different domains of QOL allow checking the dimensions of quality of life, which help to formulate effective intervention and strategies to provide an enabling supportive environment for PLHIV. Furthermore, evaluating the psychological distress and stigma among PLHIV will help identify the services needed and address issues to improve the quality of life.

1.7 Study Objectives:

1.7.1 General Objective:

This study aims to measure the quality of life (QOL), stigma, and psychological distress of People Living with HIV (PLHIV) in the Federal Territory of Kuala Lumpur.

1.7.2 Specific Objectives:

- To assess the level of quality of life (QOL) and its domains among PLHIV in the Federal Territory of Kuala Lumpur
- To assess the level of stigma and its domains among PLHIV in the Federal Territory of Kuala Lumpur
- To measure psychological distress and its domains among PLHIV in the Federal Territory of Kuala Lumpur

- To determine the association between stigma and QOL among PLHIV in the Federal Territory of Kuala Lumpur
- To determine the association between psychological distress and QOL among PLHIV in the Federal Territory of Kuala Lumpur
- To determine the association between stigma and psychological distress among PLHIV in the Federal Territory of Kuala Lumpur

1.7.3 Operational Definition

a. People Living with HIV (PLHIV)

The U.S Department of Health and Human Services defines "people living with HIV/AIDS or (PLWHA) as infants, children, adolescents and adults infected with HIV/AIDS". The UNAIDS terminology guidelines 2011 uses people living with HIV (PLHIV) with reference to those living with HIV. The terminology reflects the fact that those infected with HIV will continue to live well and being productive for many years (UNAIDS, 2011). In this study, people living with HIV are HIV seropositive person diagnosed by a medical officer and notification of disease made to the Ministry of Health.

b. Quality of Life (QOL)

The World Health Organisation defines "the quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (*WHOQOL measuring the quality of life*, 1997). QOL includes the extent of physical and emotional symptoms as well as physical, emotional, social and cognitive functioning, mobility and self-care and patient perception of health and well being (Murdaugh, 1998). The QOL measurement is used in this study to convey an overall sense of well being and satisfaction with life. It is used to describe the standard of health, comfort, and happiness experienced by the individual. This study use Malay version WHOQOL- HIV BREF for the assessment of QOL among PLHIV.

c. Highly Active Antiretroviral Therapy (HAART)

Highly active antiretroviral therapy is a combination of three or more different drugs like nucleoside reverse transcriptase inhibitors, protease inhibitor, and non-nucleoside reverse transcriptase inhibitor. Antiretroviral therapy is effective in slowing the progress of HIV by suppressing viral replication and reducing the amount of virus in the blood to undetectable levels.

d. Key Populations

UNAIDS terminology guidelines 2015 describes key populations as a “group of people whom are most likely to be exposed to HIV or to transmit it”. This includes men who have sex with men (MSM), transgender persons, people who inject drugs (PWID), sex workers and their clients and seronegative partners in serodiscordant couples. These groups have a higher risk of HIV exposure compared to others.

e. People Who Inject Drugs (PWID)

UNAIDS terminology guidelines 2015 describe people who inject drugs as persons who use drugs with subcutaneous and intramuscular routes.

f. Men Who Have Sex with Men (MSM)

MSM is described as males who have sex with the same sex (males). This is regardless of whether or not they also have sex with women, bisexual identity or is personally or socially gay (UNAIDS, 2015).

g. Heterosexual

Heterosexual is used to describe people who have sex with the opposite sex (male and female sexual intercourse).

h. Sex Workers

Sex workers include female, transgender and male who receive money or goods in exchange for sexual services. The term is used to be non-judgemental to the nature of sexual activity but focuses on the working conditions where sexual services are paid for.

i. Transgender

A transgender person is described as a person who has a gender identity different from his or her sex at birth. It includes those who are male with female identity or female with male appearance.

j. Modes of Transmission

This research describes the mode of transmission as most the probable cause or route for contracting HIV. The term is frequently used to describe HIV transmission among the key populations. UNAIDS terminology guidelines describe modes of transmission as an abbreviation of study of HIV incidence by mode of transmission.

k. Stigma

UNAIDS terminology guidelines 2015 defines stigma as “a dynamic process of devaluation that significantly discredits an individual in the eyes of others. It is described as certain attributes that are seized upon as discreditable or unworthy within particular cultures or settings (UNAIDS, 2015).

l. Discrimination

Discrimination refers to any form of exclusion or restriction affecting a person”. In the context of HIV, it is usually due to an inherent personal characteristic or perceived belonging to a particular group irrespective of whether or not there is any justification for these measures (UNAIDS, 2015). Stigma, when acted upon, will result in discrimination that may cause negative actions.

m. Perceived Stigma

Perceived stigma refers to “personal belief of an individual person that PLHIV will be discriminated or judged negatively if their HIV status is revealed” (Audet, Mcgowan, Wallston, & Kipp, 2013). Perceived stigma among the study respondents were assessed using Berger’s HIV Stigma Scale.

n. Enacted / Experienced Stigma

Enacted stigma refers to “the actual events of being stigmatised and discrimination experienced by PLHIV” (Audet et al., 2013).

o. Internalised Stigma or Self-Stigma

Internalised stigma refers to the shame and guilt as well as the negative self-image felt by PLHIV (Audet et al., 2013). Self-stigma occurs when a person cognitively or emotionally absorbs stigmatising assumptions and stereotypes about HIV and ultimately comes to believe and apply to him or herself (Drapalski et al., 2013).

p. Depression

Depression is characterised by the presence of psychological symptoms such as depressed mode, feelings of worthlessness, loss of interest or pleasure, guilt and recurrent thoughts of death or suicide. It is associated with somatic symptoms like sleep disturbance, significant weight change, fatigue, physical agitation or retardation and difficulty to concentrate (American Psychiatric Association, 2013). This study used Bahasa Malaysia version of the Depression, Anxiety and Stress Scales 21 item (DASS-21) to determine the level of depression.

q. Anxiety

The symptoms of anxiety disorder include mental symptoms of fearful anticipation, restlessness, sensitivity to noise, poor concentration, worrying thought and physical symptoms of dry mouth, breathlessness, tremor and palpitations (Olagunju et al., 2012).

Anxiety were measured in this study using the Bahasa Malaysia version of the Depression, Anxiety and Stress Scales 21 item (DASS-21).

r. Stress

Stress is defined as “the degree to which a person felt overwhelmed or unable to cope as a result of pressures that are unmanageable” (Mental Health Foundation, 2019). This study used Bahasa Malaysia version of the Depression, Anxiety and Stress Scales 21 item (DASS-21) to determine the level of stress.

1.8 The Contributions of this Thesis

This thesis provides several key contributions to the literature on QOL, psychological distress and stigma related to PLHIV in Malaysia. It provides a quantitative analysis of QOL of PLHIV receiving HIV treatment and care, and also those PLHIV not on HIV care and follow up.

This study examines significant issues. Accelerating treatment coverage, eliminating stigma and discrimination has been Malaysia’s aspiration to achieve the vision of ending AIDS by 2030. This is supported by the ARV treatment programme, which has shown promising results in increasing the lifespan of PLHIV and slowing HIV transmission. Therefore, quality of life has been an important outcome indicator to be measured among PLHIV. Although the quality of life among PLHIV has been published internationally, the issues have not been widely explored in Malaysia. Furthermore, the findings of this study will add knowledge to the existing literature. Results from this thesis also provide significant empirical evidence of the importance of addressing mental health issues among PLHIV and efforts to reduce HIV stigma and discrimination by having a better understanding and structured intervention in the community as well as in the healthcare setting. Finally, if the evaluation of depression, anxiety and stress level among PLHIV are effectively adopted into standard HIV care, it improves the quality and outcome of patient care as well as reduce the overall healthcare cost.

1.9 Thesis Outline

The thesis is written in six chapters to give clarity and easier understanding of the study. Chapter one describes the introduction of the study. It includes the research background, statement of the problem, objectives of the study, research questions and research hypothesis, operational definitions and the public health significance of the study. It also explains the rationale of the research and the underlying factors surrounding HIV/AIDS in Malaysia.

Chapter two presents a review of the literature on issues related to the quality of life among PLHIV and factors related to stigma and discrimination experienced by PLHIV and depression, anxiety and stress among PLHIV. It also includes the recommendations and gaps identified by previous studies and discusses the conceptual framework of factors related to the quality of life, articles on quality of life research from different parts of the world and other literature related to stigma and discrimination.

Chapter three consists of a detailed description of the research methodology. It describes the research design, instruments used in the study, sample size calculation, sampling method and data collection method. The pilot study, plan for analysis and ethical approval are also described.

Chapter four engages in a detailed analysis of the results or study findings according to the objectives of the study.

Chapter five discusses the findings of the study, including the results of previous studies as a comparison and to support the conclusions of the present study.

Chapter six consists of the conclusion of the study, followed by the recommendations to improve public health services, HIV-related policies and potential future research. It also describes the limitations and strengths of the study before ending with a summary of the study findings.

1.10 Summary

This chapter give an overview of HIV issues in Malaysia which were initially driven by injecting drug use and is spreading increasingly through sexual transmission among key populations and their intimate sexual partners. It also described the country responses to ending AIDS by 2030 which includes the integration of HIV services at primary health centres, improving treatment adherence and ensuring continuum of care. The Malaysia National Strategic Plan for Ending AIDS includes the reduction of stigma and discrimination initiative which is the topic of interest of this research as priority programmes to achieve better quality of life among PLHIV. However, it does not include psychological distress (depression, anxiety and stress) as a priority programme. This chapter ended by presenting the rationale of the current study in line with the research objectives. In the following chapter, literature review related to quality of life, psychological distress and stigma among PLHIV will be discussed in greater detail.

CHAPTER 2: LITERATURE REVIEW

2.1 Chapter Overview

This chapter reviews the literature concerning the quality of life among people living with HIV (PLHIV). This includes the association between psychological distress (depression, anxiety, and stress) and stigma with QOL among PLHIV. This chapter then describes the process of the systematic search to identify the relevant studies and factors that influence QOL among PLHIV. Finally, a conceptual model for this study is specified to guide the development of the study.

2.2 Quality of Life (QOL) Measures

The World Health Organisation (WHO) defines the quality of life as “the individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectation, standards, and concerns” (WHO, 1998). It is a concept which comprises the individual’s psychological state, social interaction, personal belief, independence level, coping mechanism and interaction with the environment (Hasanah, Zaliha, & Mahiran, 2011). Besides HIV, QOL has been described in many chronic illnesses like multiple sclerosis, Diabetes mellitus, hypertension, schizophrenia (Murdaugh, 1998). Many studies do use the terms health-related quality of life (HRQoL) interchangeably with the quality of life (QOL). Health-related quality of life is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. It focuses on the impact health status has on quality of life (QOL) (Yin, Njai, Barker, Siegel, & Liao, 2016) .This study use the terms QOL to describe the value assigned to the duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, treatment, and healthcare delivery (Robinson 2004).

The availability of antiretroviral treatment has slowed the viral replication and contributed to prolonging the life of PLHIV. This has resulted in a shift in conceptualising HIV as a chronic illness, where the cure is currently not possible, but death is eventually a distant (Holzemer et al., 2009). Therefore, the challenges that PLHIV face in daily living is expanding and become more challenging to sustain their life. The ability to meet these challenges will influence disease progression and their quality of life (Murdaugh, 1998). Measuring QOL has shifted from the perceptions of quality of life in the physicians or healthcare perspective to the subjective feelings of the individual's health (Bowling, 2001). QOL has also become an important outcome in evaluating disease progression or medical intervention efficacy besides traditional morbidity and mortality outcomes. Furthermore, changes in medical management from supportive care to the management of chronic disease have also increased the attention to QOL among PLHIV (Murdaugh, Moneyham, Jackson, Phillips, & Tavakoli, 2006). The Achieving a Balance theory by Murdaugh (1998) describes "the psychological adjustment process of persons with HIV disease from the time of diagnosis to their current circumstances which involve balancing the requirements of living with the progression of the disease". Therefore, QOL is used as a valid clinical outcome that reflects the patient's evaluations of the effects of the disease and its treatments on their well being.

Higginson & Carr (2001) described QOL measures in clinical practice to ensure that HIV treatment and evaluations focus on the patient himself and not the disease. QOL measures have many potentials uses in the clinical encounter and may contribute to training, reviewing care and improved care. It helps to screen for potential problems, prioritise problems and identify preferences, to facilitate communication, monitor changes or response to treatment, training of staff and can be used for clinical audit and in clinical governance (Higginson, 2001).

2.3 Model of Health-Related Quality of Life of Wilson and Cleary

Wilson and Cleary developed a model that identifies the conceptual approaches to better characterised what health-related quality of life (HRQOL) instrument measure (Ferrans, 2007). The HRQOL measure characterises what the patient has experienced as the results of medical care. They are important tools to supplements the traditional physiological or biological measures of individual health status (Wilson & Cleary, 1995). The conceptual framework of Wilson and Clearly shows the relationship between measures of patient outcomes with the quality of life as in Figure 9.

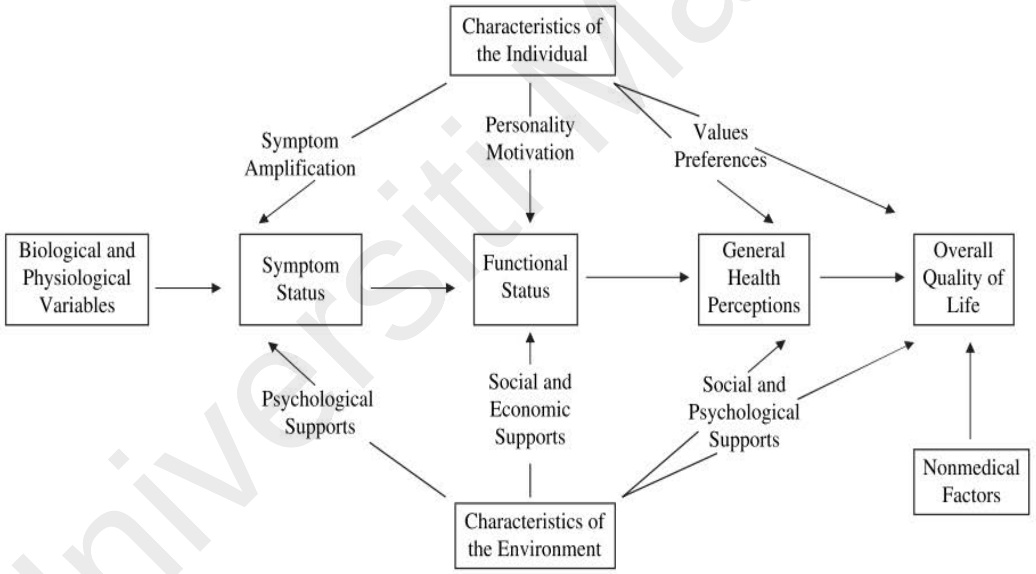


Figure 9: Relationship between measures of patient outcomes with the quality of life conceptual model

The main components of the conceptual model are the five boxes in the middle. The arrows indicate causal associations between boxes. The first component depicts the biological and physiological variables. The second box shows symptom status, which refers to the patient’s perceived physical, cognitive and emotional symptoms. The third box is functional status, which includes psychological and social functioning, as well as physical functioning. In the fourth box, general health perceptions refer to patient perceived of all the health concepts. The fifth component, which is the overall QOL refers to the patient’s evaluation of their QOL, whether they are happy or satisfied with their life. This will include measures of life satisfaction and global QOL (Ferrans, 2007). Sousa & Kwok (2006) used structural equation modelling to examine the relationships among these five domains in a sample of 917 PLHIV. The analysis supported the conceptual model of Wilson and Cleary.

2.4 Quality of Life Assessment Tools

Many tools are used to measure the quality of life, and there is no specific single gold standard for measurement. However, according to Vanhems, Toma, & Pineault (1996) “there are at least key areas where measurement of QOL must account for multidimensionality which include a) sensory function b) physical function c) emotional function d) cognitive function e) self-care ability regarding activities of daily living and f) levels of pain and discomfort”. QOL is not necessarily observable since it should be defined as an individual’s subjective experience (Pearlman & Jonsen, 1985). Therefore, QOL measurement should focus on individual self-rated measurement and not clinical assessment (Robinson, 2004).

Robinson (2004) described that there are two types of instruments used to measure the quality of life: the generic instrument and specific instrument. Generic instruments are instruments developed for use across different diseases, type of treatments and different patient’s group. Examples of validated generic instruments of QOL within the HIV-infected population include the WHOQOL-100, MOS (Medical Outcomes Study-derived quality of life measures), MOS-SF-36 (Medical Outcomes Study 36 item questionnaire), Quality of Well Being Scale and the Quality of Life Index. HIV specific QOL instruments offer clinicians or researchers a conceptually more valid assessment of QOL among PLHIV. Examples of HIV specific instruments are: WHOQOL-HIV/AIDS (World Health Organisation Quality of Life HIV/AIDS module) MOS-HIV (Medical Outcomes Study-HIV) Revised FAHI (Functional Assessment of Human Immunodeficiency Virus Infection) HOPES (HIV Overview of Problems/Evaluation). A systematic review by Dasgupta et al. (2013) and Robinson (2004) comparing six instruments specifically developed to measure QOL among PLHIV. However, the systematic review does not include the WHOQOL-HIV or WHOQOL-BREF questionnaire. A systematic review by Cooper et al. (2017) suggests that WHOQOL-HIV BREF proved to be the most cross-culturally valid measures and therefore, a good choice for international assessment of QOL in HIV.

2.4.1 WHOQOL - HIV Instruments

The World Health Organisation (WHO) has developed two instruments measuring the quality of life, namely “WHOQOL-100 and the WHOQOL –BREF”. Both are generic instruments to measure QOL that can be used in a variety of cultural settings and have been tested in 15 collaborating centres around the world (WHO, 1998). The WHOQOL – BREF is an abbreviated 26-item version of the WHOQOL – 100 items. WHOQOL instruments have been widely used in medical practices. It was used in assessing the effectiveness and relative merits of different treatments, health services evaluation to improve the doctor-patient relationship. It is also widely used in research and policy making. In Malaysia, a pilot study of the Malay version WHOQOL- 100 was conducted by Hasanah et al. (2011) and Hasanah & Razali (1999). The Malay version WHOQOL-

100 has been tested on 50 healthy controls and 250 ill respondents with many diseases like hypertension, diabetes mellitus, epilepsy, schizophrenia and among those with both hypertension and ischaemic heart disease.

WHOQOL – 120 HIV is a specific instrument developed for HIV disease from an extensive pilot and field test in ten centres around the world. In the year 2002, the WHOQOL-HIV BREF was developed based on the WHOQOL-BREF, where it contains five additional items specific to PLHIV, giving a total of 31 items WHO (2002). It has been tested suitable for assessing QOL among PLHIV across a range of different socioeconomic and cultural backgrounds. In Malaysia, validity and reliability of the Malay version of WHOQOL- HIV BREF was conducted by Saddki, et al., (2009) involving 157 PLHIV in Infectious Disease Unit, Hospital Raja Perempuan Zainab II Kota Bharu, Kelantan. The internal consistency of the five domains was good ranged from 0.70 to 0.83 and the intraclass correlation coefficient (ICC) ranged from 0.60 to 0.87 across all domains. The Cronbach's alpha values for each domain were at least 0.70 and was lowest in the social domain. Test – retest reliability of the Malay version of WHOQOL-HIV BREF ranged from 0.60 to 0.87 which is comparable to the reliability of the generic WHOQOL-BREF.

2.5 Systematic Review of HIV and Quality of Life Research in Malaysia and South East Asia

Currently, limited information is available regarding the QOL among PLHIV in Malaysia. There were more QOL studies among PLHIV in other parts of the world. The review aimed to identify QOL among PLHIV and its association with psychological distress, stigma and use the information as a basis to create a model regarding factors influencing QOL among PLHIV.

2.5.1 Search Strategy

A search protocol was developed for the systematic extraction of relevant articles. Figure 11 summarises and illustrates the flow of the article selection. The MeSH database in Pubmed and the Emtree subject heading in Embase bibliographic database were searched for relevant literature. The searched terms were “People Living with HIV” AND “Quality of Life” OR “health-related quality of life” AND “depression” OR “anxiety” OR “stress” OR “stigma”. The search was limited to articles in English. The search period was updated until 30 June 2018. Eligible studies were those meeting the following inclusion criteria:

i. Observational studies
ii. Quantitative studies
iii. Involving adults PLHIV
iv. Outcome measured was QOL, depression, anxiety, stress, and stigma
v. Proper data analysis with correlation as the minimal statistical analysis. The highest order statistical analysis will be used as the final finding.
vi. Validated tools/ questionnaires used
vii. Full article must be available

The exclusion criteria were:

i. Non-PLHIV respondents or other clinical diagnosis like Diabetes, Tuberculosis
ii. Paediatric patients
iii. Inpatients clinical respondents
iv. Pregnant mothers

The search yielded 2,982 titles in Pubmed and 1,431 in Embase. After screening the titles, 3994 titles were excluded while the abstract of the remaining 419 titles was obtained and retrieved from the combination of keywords with full texts inclusion. A further review of abstracts with exclusion criteria resulted in 252 studies reported on the QOL among PLHIV. The QOL tools used in the studies varied. However, generally, they measure QOL among PLHIV. The corresponding relevant full articles were retrieved. Finally, only 35 full articles were chosen for the review.

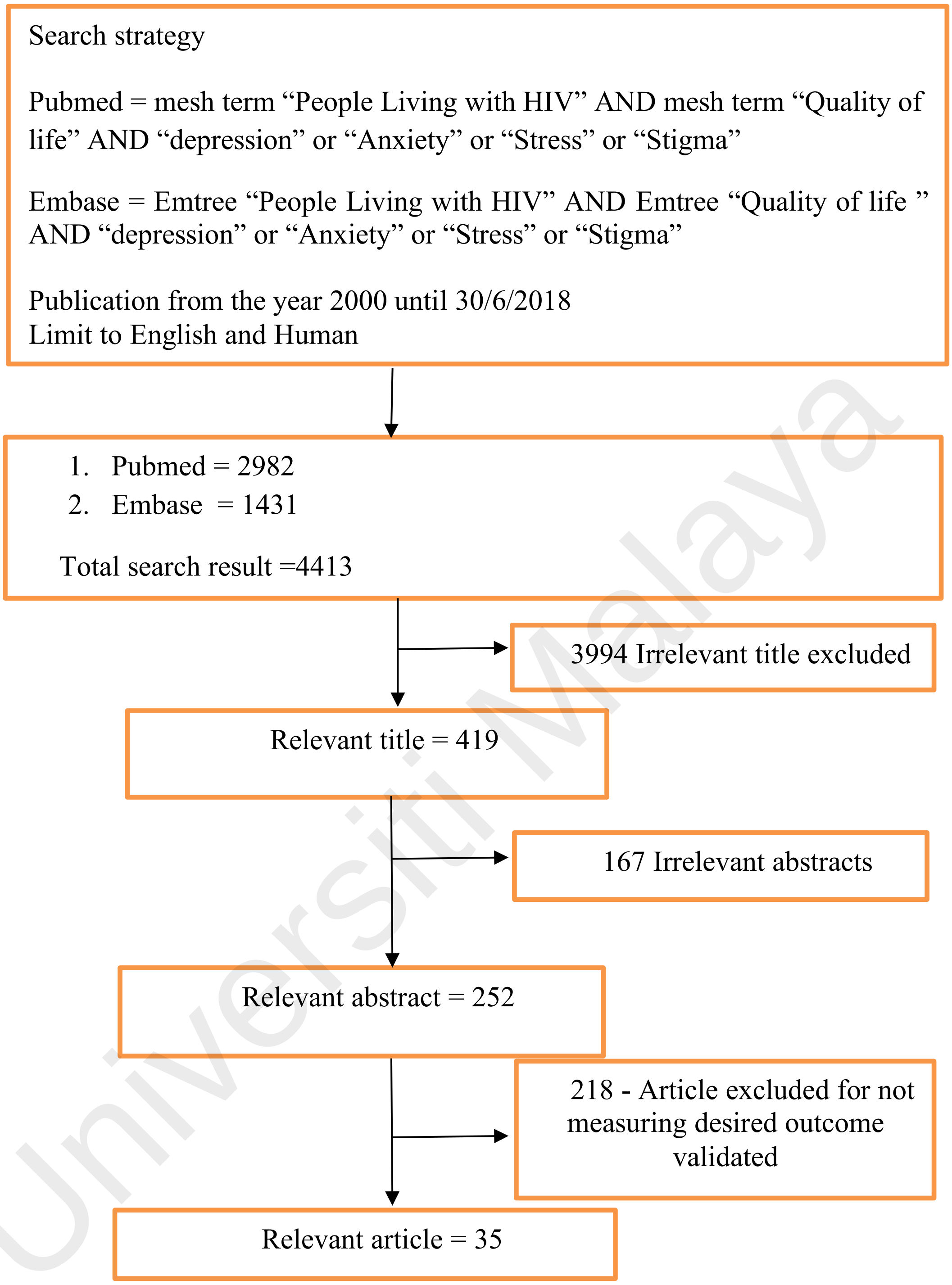


Figure 10: Flow of studies through literature search strategies

Table 2. 1: Evidence table of selected articles

Author / Year	**Study design**	**Location**	**Sample**	**Measures (Tools)**	**Findings**
(Hasanah et al., 2011)	Cross-sectional convenience sampling	ID clinic. Kelantan	n = 271 male= 57.6% female= 42.4%	(QOL) FAHI (functional assessment of HIV) - Malay version. (Depression) HADS (hospital anxiety depression scale)- Malay version.	• Good physical domain and impaired social domain • Non-disclosure had a greater effect on social well being. • 38% had anxiety, depression and significantly associated with FAHI and its domain.
(Choi et al., 2010)	Cross-sectional convenience sampling	Pengkalan Chepa Prison, Kota Bharu	n= 102 (all males)	(HIV Stigma) Berger HIV Scale	• High levels of stigma including negative self-image and public attitudes stigma were associated with difficulty obtaining HIV care.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Zaidi et al., 2012)	Cross-sectional Convenience sampling	Three HIV shelter managed by Islamic Organisations in Klang Valley.	n= 27 male=96.3% female=3.7%	(QOL) WHOQOL-HIV BREF	• Improvement in QOL in all 6 domains within the WHOQOL-HIV BREF. • Shelters promoted better acceptance and support from family, friends and the community.
(Chua & Han, 2014)	Cross-sectional purposive sampling	Five NGO's in Malaysia	n= 117 shelter homes =42% drop-in centre =58% male=74.8% female=25.2%	(QOL) HIV/AIDS Targeted Quality of Life (HAT-QoL)	• PLWH who were employed, homosexual or bisexual had higher health worries. • Overall physical and psychological condition of PLWH from drop-in centres are better than shelter homes.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Othman et al., 2015)	Cross-sectional outpatient convenience sampling	ID clinic in HRPZ, Kota Bharu Kelantan	n=100 male=60% female=40%	(Depression, anxiety and stress) DASS-21 (HIV stigma) HIV Stigma Scale	• Depression, anxiety and stress occurred in 28%,6% and 2%. • Female were significantly more depressed than male. • The Islamic religiosity practice was correlated with lower emotional distress, depression, anxiety, and stress and fairly correlated with disclosure concerns.
(Othman et al., 2015)	Cross-sectional study convenience sampling	ID clinic, HRPZ Kota Bharu Kelantan	n= 100 male= 60% female=40%	(HIV stigma) HIV Stigma Scale	• There was significant gender difference for depression where female was more depressed. • There was no significant correlation between religiosity and stigma except for disclosure of HIV status.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Abdul Bari & Aida, 2017)	Cross-sectional convenience sampling	Urban primary care clinic in Kuala Lumpur	n= 288 male= 86.8% female= 13.2%	(QOL) WHOQOL- HIV BREF (HIV Stigma) HIV Stigma Scale	• The overall QOL was low with impaired in social relationship domain. • Majority participants was afraid disclosing their disease status. • Personalized stigma or prejudice and rejection was least experienced.
(Khumsaen et al, 2011)	Cross-sectional outpatient convenience sampling	Rural clinic for HIV Thailand.	n= 120	(QOL) WHOQOL- HIV BREF	• Age, education level, employment status, monthly income, living in own house, living with family members, social support, spiritual distress and coping style and adaptation process were related to QOL.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Evi, Thongpat, & Nitirat, 2017)	Cross-sectional purposive sampling study	Community HIV clinic in Adam Malik Hospital, Medan, Indonesia	n= 111 (all women)	(QOL) WHOQOL- HIV BREF	• Good QOL especially in physical domain followed by an environmental domain. • Lowest mean score was in social domain with more than half (55%) reported a poor QOL.
(Martina, Thongpat, & Nitirat, 2015)	Cross-sectional purposive sampling study	Community HIV clinic in Adam Malik Hospital, Medan, Indonesia	n= 111 (all women)	(QOL) WHOQOL-BREF	• Significant predictors of QOL in HIV infected women were social support, functional status and general health perception which explained 66.9% variance in QOL.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Srisorrachatr et al, 2013)	Cross-sectional study with cluster sampling method	Registered community-based organization (CBO) in Yangon	172 (all women)	(QOL) WHOQOL-BREF	• QOL mean score was 79.7 with physical and social domain was the highest score, and the psychological and environmental domain was the lowest. • There were 64.5% had low level of stigma and only 0.6% experienced high level of perceived stigma.
(Yi et al., 2015)	Cross-sectional using two-stage cluster sampling from CBOs	Six provinces in Cambodia	n=1003 male= 32.8% female= 67.2%	(HIV Stigma) HIV Stigma Index	• The proportion of PLHIV reported fear of stigma and discrimination ranged from 13.9% for fear of being physically assaulted to 34.5% for fear of being gossiped about.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Mutabazi et al , 2015)	Prospective cohort study	Outpatient Clinic in referral hospital in India	n=1274 male=29% female=71% ART=50%	(QOL) Medical Outcomes Study (MOS-HIV) (Psychological distress) Mental Health Summary (MHS)	• Quality of life improved over time for PLHIV on ART. • Depression or low education level and female gender were having a poor quality of life.
(Osei-Yeboah et al., 2017)	Cross-sectional study convenience sampling	PLHIV patient attending ARV clinic Volta Regional Hospital and Ho Municipal Hospital	n=158 male=26.5% female=73.4%	(QOL) WHOQOL-HIV BREF	• Religious/personal beliefs is the most affected component, followed by the physical and level of independence domains of QOL. More than 80% of respondents had excellent and good overall QOL while 11% had negative effect of HIV in life.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Imam et al , 2011)	Cross-sectional, convenient sample of	Three NGOs and one hospital in India	n= 82 male=57.3% female 42.7%	(QOL) WHOQOL-HIV BREF	• Majority of respondents were with low QOL in all the domains of HQOL. • Low QoL was highest in the domain of social relationship (64.6%) followed by psychological domain (59.8%), physical domain (58.5%), level of independence domain (56.1%), environmental domain (52.4%) and spirituality domain (52.4%) of HQOL.
(Basavarajaiah et al, 2012)	Prospective cohort study	ART centers of Bangalore city, India	n=800 male=58.1% female=41.2% transgender=0.6%	(Quality of Life) WHOQOL-HIV BREF	• HAART treatment, educational status, and good social relationships improve the QOL.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(S & Regmi K, 2014)	Cross-sectional study convenience sampling	HIV centers in Kathmandu, Nepal.	n= 154 male= 55.48% female= 44.52%	(Psychological distress) Beck Depression (Quality of Life) WHOQOL-HIV BREF	• The prevalence of depression was found higher in TB-HIV coinfected people than HIV/AIDS group.CD4 count, educational status, occupation, ethnicity, family size, and depression were statistically significant with the QoL domains.
(Rüütel, Pisarev, Loit, & Uusküla, 2009)	Cross-sectional convenience sampling	Infectious disease clinics in Tallin, Estonia	n=451 male=53.2% female=46.6%	(Quality of Life) WHOQOL-HIV BREF	• Good overall quality of life was reported by 42.6%. • Being currently employed or studying (AOR: 2.27, 95% CI: 1.18–4.38); and the absence of HIV-related symptoms were independent predictors of good overall quality of life.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Chandrakanth.B.K, 2017)	Cross-sectional convenience sampling	District hospital of Karnataka States.	n=120 male=50% female=50%	(Quality of Life) HAT Quality of Life Self–esteem scale (HAT QOL)	• Female shows greater quality of life as compared to male counterparts. • Significant and positive correlation between quality of life and self-esteem of people living with HIV/AIDS.
(Tang, Zhang, Bo, Zhao, & Lu, 2015)	Cross-sectional convenience sampling	PLHIV from registered clinic in Henan Province	n=266 (gender not specified)	(Quality of life) WHOQOL-HIV BREF	• Female with HIV/AIDS had worse QOL than male in rural China. • Depression, clinical symptoms, support from family, income/outcome, and gender were the important factors influencing QOL of PLWHA in rural China.

Table 2.1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Charles et al., 2012)	Community-based cross-sectional study	ART Centres, PLHA network and NGOs from 7 districts of Tamil Nadu, India.	n= 400 male=47% female=53%	(Stigma) HIV stigma scale (Psychological distress) Major Depression Inventory (MDI) (Quality of life) WHOQOL-BREF Scale	• 27% of PLHA had experienced severe forms of stigma. • Severe depression was 12% and those experiencing poor quality of life were 34%. • Poor QOL reported in the physical, psychological, social and environmental domains was 42.5%, 40%, 51.2% and 34% respectively.
(Karkashadze et al , 2017)	Cross-sectional convenience sampling	HIV-infected outpatient from National AIDS Centre in Georgia	n=201 male=72.1% female=27.9%	(Quality of life) WHOQOL-HIV BREF	• Being younger than 40 years and those with lower education level are more likely to have poorer QOL. • Those receiving ARV treatment tend to have better QOL.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Morandi et al., 2007)	Cross sectional convenience sampling	Specialized University clinic in Sau Paulo	n=365 male=63% female=37%	(Quality of life) WHOQOL BREF	• PLHIV have better (physical and psychological) quality of life than other patients but lower quality in social relationships domain.
(Razera, Ferreira, & Bonamigo, 2008)	Cross-sectional study convenience sampling	Outpatient clinic in the State of Rio Grande, Brazil	n=367 male=63.5% female= 36.5%	(Quality of life) WHOQOL-HIV BREF	• Being unemployed was associated with a worse QOL in five out of six domains; the only exception was the domain of spirituality. • Socioeconomic aspects were most significant in determining the HQOL.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Kovacević, Vurusić, Duvancić, & Macek, 2006)	Cross-sectional study convenience sampling	University Hospital for Infectious Diseases in Zagreb, Croatia.	n=111 male=78.4% female=21.6%	(Quality of life) WHOQOL-HIV BREF	• The findings demonstrate a moderate degree of overall quality of life. • Subjects who were in relationships gave higher ratings for the social relationship domain • Subjects with higher level of education gave significantly higher ratings within the independence and environment domains.
(Xiaoyan & Sato, 2011)	Cross-sectional convenience sampling	Infectious Disease Clinic in Hubei Province, China	n=94 male=50% female=50%	(Quality of life) WHOQOL-HIV BREF	• Best quality of life in level of dependence, poorest quality of life in social relationships domain • Quality of life was statistically related to gender, CD4 counts and perceived social support.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(I. A. Wakawa et al., 2014)	Cross-sectional case-comparison study between HAART and diabetic group	Outpatient clinics in the University of Maiduguri Teaching Hospital in North-eastern Nigeria.	n=303 male=54.1% female=42.4%	(Psychological distress) Beck Depression Inventory (Quality of life) WHOQOL- BREF	• Prevalence of depression was 20.5% in the HIV subjects against 8.3% in the diabetics ($\chi2=17.46$, $p=<0.001$). • Depressed respondents rated their HRQOL poorer than nondepressed respondents on the physical, psychological, social relationships and environmental domains.
(Adewuya et al., 2008)	Cross-sectional with stratified random selection	HIV support care centre in Ilesa, Western Nigeria	n=87 male=43.7% female= 56.3%	(Psychological distress) Mini International Neuropsychiatric Interview (MINI) (Quality of life) WHOQOL BREF	• Poorer health-related QOL in Nigerian subjects with HIV was associated with depression, lower educational and socioeconomic levels, and poor social support.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Folasire, Irabor, & Folasire, 2012)	Cross-sectional convenience sampling	ARV clinic at the University College Hospital in Ibadan, Nigeria.	n=150 male= 38% female= 62%	(Quality of life) WHOQOL-BREF	• High QOL scores in the physical, psychological and environmental domains • Low social domain scores may suggest ineffective social support networks, because PLWHA are still exposed to stigmatization and discrimination.
(Poupard et al., 2007)	Cross sectional convenience sampling	Dakar, Senegal	n=200 male=36.5% female=63.5%	(Psychological distress) Center for Epidemiologic Studies Depression Scale 20 (CES-D 20).	• Only 18% of patients had depressive symptoms. • Quality of life remained good in depressed group of respondents.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Keaei et al., 2016)	Cross-sectional convenience sampling	Outpatient PLHIV receiving antiretroviral therapy in Bogotá.	n=181 male=77.5% female=22.5%	(Quality of life) EuroQol five-dimensional questionnaire (EQ-5D-5L) EuroQol visual analogue scale (EQ-VAS)	• The HRQOL scores of patients with HIV/AIDS receiving antiretroviral therapy were relatively high.
(Martin, Russell, & Seeley, 2014)	Cross-sectional study convenience sampling	Communities in Wakiso District, Uganda.	n=423 male=32.7% female=67.3% PLWH on ART (n=263) and participants not on ART (n=160)	(Quality of life) WHOQOL-BREF	• Better QOL amongst PLWH on ART compared to a general community sample, which cannot be explained solely by differences in socio-economic status nor location of residence.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(Nglazi et al , 2014)	Cross-sectional study convenience sampling	Cross roads community health clinic in Cape Town	n=903 male=22.8% female=77.2%	(Quality of life) Visual Analogue Scale (EQ-5D VAS)	• Subject's EQ-5D VAS scores improved significantly on ART, suggests that drug toxicities, especially those related to d4T have little impact on subjects self-rated health.
(George et al , 2016)	Cross-sectional study convenience sampling	PLHIV enrolled in the Dublin HIV Cohort study from the GUIDE clinic.	n=521 male=69.3% female=30.7%	(Quality of life) Medical Outcomes Study HIV (MOS-HIV) Health Survey HIV/AIDS Targeted QoL questionnaire (HAT-QoL)	• Overall HRQOL in this study had an average level of QOL. • CD4 count and viral load do not reflect the effects of HIV on their HRQOL.

Table 2. 1: Evidence table of selected articles. Continued

Author / Year	Study design	Location	Sample	Measures (Tools)	Findings
(M.-C. C. Feng et al., 2015)	Cross-sectional study convenience sampling	PLHIV from clinic and ward in a medical center in southern Taiwan.	n=200 male=96% female= 4% Homosexual =83%	(Psychological well being) Stress and needs scales were developed for this study (Quality of life) WHOQOL BREF	• The QoL of PLWHA can be explained by demographics, self-perception on health, needs, and stress for 25.3 to 40.7% of variances. • No association existed between CD4 counts and QoL in Taiwanese PLWHA. • PLWHA generally demonstrated poor QoL, and their stress was the most significant single factor for this.

2.6 Summary of the Published Literature

2.6.1 Description of the Studies

There were 35 relevant full articles identified from 34 individual studies. Twenty-one studies were on quality of life among PLHIV, six studies on the association between stigma and QOL and nine studies described the association between psychological distress and QOL.

2.6.2 Study Design

Only two studies utilised a cohort study design, and most (32) were cross-sectional. The primary limitation of a cross-sectional study is that it offers no evidence of a temporal relationship between exposure and outcome since both are assessed simultaneously.

2.6.3 Samples and Sampling Methods

The number of participants in each study ranged from 27 to 1274 respondents. Convenience sampling or purposive sampling methods were mostly applied for this type of study (involving 30 studies). A study used stratified random sampling technique in Nigeria, the two-stage cluster sampling in Cambodia and cluster sampling method in Yangon.

2.6.4 Measurement and Instruments

For the quality of life outcome measurement studies, 11 studies used the WHOQOLHIV-BREF while 11 studies used the WHOQOL-BREF questionnaire. There were two studies used HIV/AIDS Targeted Quality of Life (HATQOL) and one each using functional assessment of HIV (FAHI), EuroQol five-dimensional questionnaire (EQ-5D-5L), Medical Outcomes Study (MOS-HIV) and EuroQol visual analogue scale (EQ-VAS).

The tools used to describe psychological distress including depression, anxiety and stress scale (DASS-21), hospital anxiety depression scale (HADS), Beck Depression Inventory Scale II, Major Depression Inventory (MDI), Mini International Neuropsychiatric Interview (MINI), Centre for Epidemiologic Studies Depression Scale 20 (CES-D 20). Tools used to measure stigma were HIV Stigma Scale and HIV Stigma Index.

2.6.5 Geographical Location

Seven studies were conducted in Malaysia, three in India and Nigeria, two in Indonesia, Brazil and China, and one study in each of the following countries, namely, South Africa, Bangladesh, Thailand, Cambodia, Columbia, Senegal, Croatia, Georgia, Uganda, Estonia, Nepal, Ghana, Taiwan, and Myanmar.

2.7 Factors Associated with QOL Identified from the Systematic Review

Education level

Five studies investigated the relationship between education level with QOL. All studies reported those with higher education reported higher QOL in PLHIV (Adewuya et al., 2008; Basavarajaiah, Murthy, and Leelavathy, 2012; Catalan, Tuffrey, Ridge, & Rosenfeld, 2017; George et al., 2016; Kovacević et al., 2006; Monteiro, Canavarro, & Pereira, 2016; Mutabazi-Mwesigire, Katamba, Martin, Seeley, & Wu, 2015a). PLHIV with a higher education level coped better with HIV

(Mutabazi-Mwesigire et al., 2015). Respondents with a higher level of education have significantly higher ratings in the independence and environment domain (Kovacević et al., 2006).

Age

Very limited studies described age as influencing QOL. In a study involving HIV patients aged over 50 years, it was observed that middle-aged and older patients had significantly lower QOL in physical, independence and social relationships domains (Monteiro et al., 2016). However, a study among PLHIV age over 50 years in the United Kingdom showed that half of the participants reported good and very good QOL (Catalan et al., 2017).

Gender

Men have better QOL than women in the psychological and spiritual domain. Being female was a determinant of a low QOL in the absence of antiretroviral treatment (Catalan et al., 2017). In contrast, Fatiregun, Mofolorunsho, & Osagbemi (2009) showed better QOL among women. In China, gender inequalities may have an impact on women's QOL with lower QOL among females (Xiaoyan & Sato, 2011). Kovacević et al. (2006) reported no difference in QOL with regards to gender.

Highly Active Antiretroviral therapy (HAART)

Initiation of antiretroviral therapy as a clinical intervention has successfully prevented HIV transmission and slowed the progression of HIV infection in infected PLHIV (Oguntibeju & Oguntibeju, 2012). Five studies investigated the role of antiretroviral in QOL. All studies described that there were statistically significant improvements in QOL scores while on HAART (Basavarajaiah. et al., 2012; Doris et al., 2004; Martin et al., 2014; Mutabazi et al., 2015; Oguntibeju, 2012; and Osei-Yeboah et al., 2017). Besides the initiation of HAART, adherence to HAART is an important factor. Mannheimer et al. (2005) concluded that PLHIV with less than 80% adherence to HAART had lower QOL and PLHIV with good adherence to HAART having better QOL. The Highly Active Antiretroviral therapy (HAART) was negatively associated with physical domain due to adverse side effect experienced by the patient on HAART. Therefore, a patient with poor adherence to HAART did not get the benefit of the treatment and will experience a negative impact. Patients who were not on ART had significantly poorer QOL as against patients on HAART for spirituality/religiosity/personal beliefs of QOL domain (Osei-Yeboah et al., 2017).

Psychological Distress (Depression, Anxiety, Stress)

Nine studies described the association between psychological distress (depression, anxiety, and stress) with QOL. Hasanah et al. (2011) showed that 38.4% of the subjects had depression, anxiety or both on screening with Hospital Anxiety and Depression Scale. Othman et al. (2015) used the DASS scale among PLHIV in Kelantan and showed that 28% depression, 6% anxiety and 2% stress with females significantly more depressed than males. In Nigeria, Wakawa et al. (2014) reported the prevalence of depression among PLHIV was 20.5%, while in Senegal, depression was 18% (Poupard et al., 2007) and severe depression was 12% in India (Charles et al., 2012). Seven studies (Adewuya et al., 2008; Charles et al., 2012; Hasanah et al., 2011; Mutabazi-Mwesigire et al., 2015; Othman et al., 2015; S & Regmi K, 2014; I. A. Wakawa, Sale, Kwajafa, Beida, Musa, et al., 2014) reported that depression consistently appeared as significant associations with lower QOL. A study in Taiwan by Feng et al. (2015) described stress as the most significant factor in influencing QOL. Life stressors among PLHIV include HIV specific stressors and non-HIV specific life stressors like poverty, unemployment, homeless, violence, stigma and discrimination (Fang et al., 2016).

Stigma and Discrimination

Stigma not only affects those infected with HIV but extends to those affected by the disease, which includes family members, co-workers, and friends. HIV-AIDS related stigma can be manifested in three main ways where PLHIV may experience judgemental stigmatising attitudes, they may also have feelings of becoming discredited, tainted and discounted when they disclose their HIV serostatus and finally, PLHIV may have the belief that they deserve to get the disease (Berger, Ferrans, & Lashley, 2001).

Stigma is a social process that exists when there is elements of labelling, stereotyping, separation, loss of status and discrimination towards an individual (Link, 2006). Enacted stigma is the actual experiences of discrimination while perceived or internalised or also known as felt stigma is the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself (Corrigan, Watson, Warpinski, & Gracia, 1993). Stigma will affect PLHIV psychologically, often lower their self-esteem and may cause or aggravate psychiatric morbidity. Both enacted and perceived stigma will restrict social participation and on a bigger scale will be harmful to public health programmes. Media plays a powerful role in perpetuating or mitigating stigma through images portrayed and educational materials in the media. Therefore, they can serve as an indicator of changing attitudes towards people with stigmatised conditions and can be a powerful change agents (Van Brakel, 2006).

Holzemer et al. (2009) described stigma independently contributed around 5% variance in QOL, after removing confounders like HIV-related symptoms and severity of illness. The study explores the potential negative contribution of perceived HIV stigma to QOL among PLHIV. Therefore, interventions to reduce HIV- stigma have the potential to improve access to care, adherence to medication and ultimately improve the QOL among PLHIV.

Employment Status

Employment plays an important role in a person's life. Blalock, Stephen Mcdaniel, & Farber (2002) showed that unemployed individuals reported more depression, anxiety, social isolation, and low self-esteem than employed individuals. Unemployment was also associated with suicidal ideation among PLHIV. However, while employment is associated with improved overall QOL, its relationship to psychological functioning is a complex phenomenon that requires further investigation (Blalock et al., 2002).

Demographic Age

Most of the PLHIV were in the younger age group, the availability of antiretroviral treatment slowly prolonged the life span of PLHIV. The issue regarding whether ageing influences the QOL was described by Avis & Smith (1998). The study showed that older PLHIV were more likely to rate social activities, living conditions and religion as important while the younger age group rate relationships, finances, work and happiness as important. This shows a different perspective of QOL between the two groups of PLHIV. The post HAART era has made it possible for many PLHIV to age successfully. Since PLHIV live longer with an increasing number of older PLHIV patients, physicians need to be prepared for these trends and be familiar with HIV management in older patients (Nguyen & Holodniy, 2008). Vance et al. (2011) suggested that successful ageing among PLHIV composed of eight factors "length of life, biological health, social competence, cognitive efficiency, mental health, productivity, personal control and life satisfaction".

HIV Viral Loads, CD4 Counts

The availability of advanced medical technology has helped facilitate the monitoring of the patient's disease progress and help clinicians make decisions regarding intervention and treatment of opportunistic infection to reduce morbidity and mortality. However, one study in Taiwan found no association between CD4 count and QOL (Feng et al., 2015). George et al. (2016) reported that the routinely assessed CD4 count and viral load did not reflect the direct effect of HIV on QOL. The study suggested a regular assessment of QOL using reliable a method would help better understand the effects of HIV treatment on people's lives and facilitate the holistic management of HIV. Gill (2002) showed that higher CD4 counts were associated with better QOL. Undetectable viral load was associated with good physical functioning domain in QOL. Xiaoyan & Sato (2011) reported lower mean QOL scores in patients having CD4 counts < 200 compared to those with CD4 > 500.

Spiritual Well Being

Spiritual well being, social support, and coping were described by Khumsaen et al. (2011) in Thailand. WHOQOL SRPB GROUP (2006) included 18 participating field centres in the Americas, Europe, Middle East, Africa, Japan, Thailand and Malaysia. The findings showed that spiritual, religious and personal beliefs (SRPB) were highly correlated with all WHOQOL domains, especially the psychological and social qualities. People who reported SRPB domain regained prominence along with the physical domain, psychological and environmental domains had poorest health. Furthermore, Connell & Skevington (2009) reported that spiritual QOL made a significant independent contribution, like the other five QOL domains.

Health-Promoting Behaviour and Physical Activities

Health-promoting behaviours are actions directed to increase well being, self-actualisation, and fulfilment of a healthy lifestyle. It includes health responsibility, physical activity, healthy nutrition, interpersonal relationship skills and stress management (Walker et al., 1987). Uphold et al. (2007) examined the relationships between health-promoting behaviours, risk behaviours and QOL among PLHIV attending infectious disease clinics. The study showed that health-promoting behaviours and physical activity were positively associated with all QOL dimensions. It was among the first studies showing that healthy eating was related to better QOL. The study advocated that simple and straightforward changes in lifestyles such as eating well, managing stress and remaining active may result in significant improvements in QOL. These results emphasised the need to integrate health promotion counselling to the healthcare management of PLHIV and the importance of helping PLHIV to make healthy lifestyle choices. Ciccolo, Jowers, & Bartholomew (2004) described the benefits of an aerobic exercise programme of three to five sessions per week with 20 to 60 minutes per session up to eight to 12 weeks has resulted in reduced fatigue, anxiety and depressed mode, together with positive improvement of QOL.

Personal Traits

Penedo et al. (2003) suggested that individuals with personality traits associated with tendencies to experience greater anxiety, depression and fearfulness reported poorer overall QOL. However, positive personality traits such as conscientiousness, agreeableness, and extraversion were associated with better QOL. They also found that individuals who scored higher in assertiveness, trust and competence reported better QOL.

Coping Style and Adaptation Process

Khumsaen et al. (2011) showed a significant correlation between coping style and adaptation process with QOL. This was explained by the acceptance and support of the family members, and the community encouraged PLHIV to cope better with their illness. Those who did not reveal their status experienced higher stigma and discrimination in the community, which resulted in poor coping and adaptation process among PLHIV.

Substance Abuse, Smoking, Alcohol

Most studies did not include risk behaviour as predictors of QOL due to its possible negative effects. However, Uphold et al. (2007) had a contrary hypothesis where risk behaviours were not related to most dimensions of QOL. The study showed that hazardous alcohol, which is having more than 14 drinks per week or more than four drinks on a given occasion in a week, was not associated with poor QOL. Recreational drug and unsafe sexual behaviours were also unrelated to QOL. The study also described short term benefit of tobacco use.

HIV Clinic Follow and PLHIV Loss to Follow- up (LTFU)

Activities during HIV clinic follow up is of paramount importance and includes measuring the immunovirological status, optimise antiretroviral therapy, screening for HIV-related morbidity and delivering HIV prevention messages (Nacher et al., 2006). Haddow and Edwards (2003) reported that the National Strategy for Sexual Health and HIV in the United Kingdom aimed to reduce the pool of undiagnosed HIV infection due to the potential benefits of early diagnosis enhanced by having followed up at HIV clinics. HIV follow up activities include timely initiation of highly active antiretroviral therapy (HAART) to eligible PLHIV, effective prevention of HIV transmission, reduce complications related to HIV disease and screening for STIs.

Loss to follow up (LTFU) is defined by Nacher et al. (2006) as “patients coming back after more than 1 year”. Gerver et al. (2010) define loss to follow up as “clinic non-attendance for one or more years”. Patients who were lost to follow up may discontinue ART and resulted in accelerated CD4 count declined, which will continue to decline based on the natural physiology of HIV. They have increased risk of morbidity and mortality compared to those PLHIV on follow up (Losina et al., 2009). Those LTFU are generally more ill than those who are on follow up and may experience poorer long-term outcomes (Brown et al., 2006).

Nacher et al. (2006) described factors affecting loss to follow up as including younger patients not receiving any treatment, PLHIV diagnosed with HIV with CD4 less than 500mm/^{3} at the time of diagnosis, and higher among foreigners and immigrants. While Haddow and Edwards (2003) include having a less severe illness, those with drug addiction and patients health beliefs as factors affecting LTFU. Loss to follow up may appear in all stages of the disease and is not necessarily those who lack clinical needs. Losina et al. (2009) showed higher rates of LTFU ranging from 5% to 40% within six months of antiretroviral therapy initiation in West Africa and up to 59% at some point after antiretroviral. Nacher et al. (2006) reported a high incidence rate of LTFU with 17.2 per 100 person-years for an observation period of 3,839 years and Gerver et al. (2010) reported more than 30% or one in five PLHIV in London clinics were LTFU.

Therefore, LTFU prevention strategies bring substantial survival benefits and cost-effective health management. In newly diagnosed PLHIV, it is critical to combine interventions with programmes that maximise HIV care and ART initiation, which will prevent LTFU (Losina et al., 2009). Gerver et al. (2010) stated that other measures used to minimise LTFU includes text messaging reminders to patients' mobile phone before scheduled appointments, reducing the number of initial clinic visits with multidisciplinary team follow up, regular review of patients with missed appointments to make early tracing of patients and early appointment of PLHIV with peer support workers.

2.8 Quality of Life in Malaysia

Seven studies on quality of life, stigma and psychological distress were reported in Malaysia. Four studies related to the quality of life among PLHIV were reported in different settings. One study involved PLHIV in the infectious disease clinic in Kota Bharu (Hasanah et al., 2011), another study was conducted among PLHIV in the urban community clinic in Kuala Lumpur (Abdul Bari & Aida, 2017). Zaidi et al. (2012) involved PLHIV in the HIV shelter homes managed by Islamic organisations, and the fourth study was conducted among PLHIV at drop-in centres and shelter homes (Chua & Han, 2014). Current study uses various sources of recruitment of PLHIV from HIV clinic in tertiary hospital setting, HIV clinic in primary care and the Community Based Organisation (CBOs) to get better understanding on quality of life of PLHIV in FT Kuala Lumpur.

Three studies described stigma among PLHIV in Malaysia. Choi et al. (2010) studied HIV-infected male prisoners in Pengkalan Chepa Prison, Kota Bharu and two studies explored outpatient infectious disease clinic in Kota Bharu, Kelantan (Fadzil & Zahiruddin Othman, 2016) and primary care clinic in FT of Kuala Lumpur (Abdul Bari & Aida, 2017). Finally, two studies, Othman et al. (2015) and Hasanah et al. (2011) described psychological distress (depression, anxiety and stress) among PLHIV attending outpatient infectious disease clinic in Kota Bharu, Kelantan using different measurement tools. Current study described stigma and psychological distress among PLHIV loss to follow up from CBOs which was never reported before in Malaysia.

Norazah Zulkifli, Huang, Lee, & Lin (2007) studied the impact of HIV on PLHIV, their families, and community in Malaysia. This was a mixed quantitative and qualitative study that examined stigmatisation and discrimination comprehensively. Evidence from this study showed that participants that were HIV positive, irrespective from which group of the population they belong to, they were facing fear, stigmatisation and discrimination. Some experienced insults, harassment, ridicule, and humiliation. Real or perceived stigma affects their QOL and denies them social and economic equalities. It discourages them from seeking employment due to pre-employment medical disclosure and discourages them from seeking healthcare regularly. From the focus group discussion, there was more discrimination in Kota Bharu as compared to Kuala Lumpur. This was due to a lack of understanding about the disease, and the conservative society may also play a part in fostering prejudice against socially deviant behaviour such as drug use. In contrast, participants from Kuching and Kota Kinabalu experienced less stigmatisation and discrimination. This could be because infected partners and the families of the others (sex worker) may not be aware of their commercial sex work and hence are viewed as innocent victims.

The limited studies pertaining to the association between stigma, psychological distress and level of QOL among PLHIV served as a basis for this thesis. This thesis aims to fill this lacuna in the literature.

2.9 A Conceptual Model of Factors Influencing Quality of Life Among PLHIV

Based on the review in section 2.7, a conceptual model was developed to guide this study. Age, sex, education level, depression, anxiety, stress, employment status and stigma were included in a conceptual model which aimed to investigate factors influencing QOL among PLHIV. A conceptual model on how these variables relate to QOL and each other was hypothesised. Other aspects such as personal traits, health-promoting behaviour, coping style and adaptation process and substance abuse, smoking and alcohol use, which are outside the scope of this thesis were not included in the study. Figure 11 illustrates how the selected factors and stigma influence QOL and how they are associated with one another. Figure 12 illustrates how the selected factors and psychological distress influence QOL and how they are associated with one another.

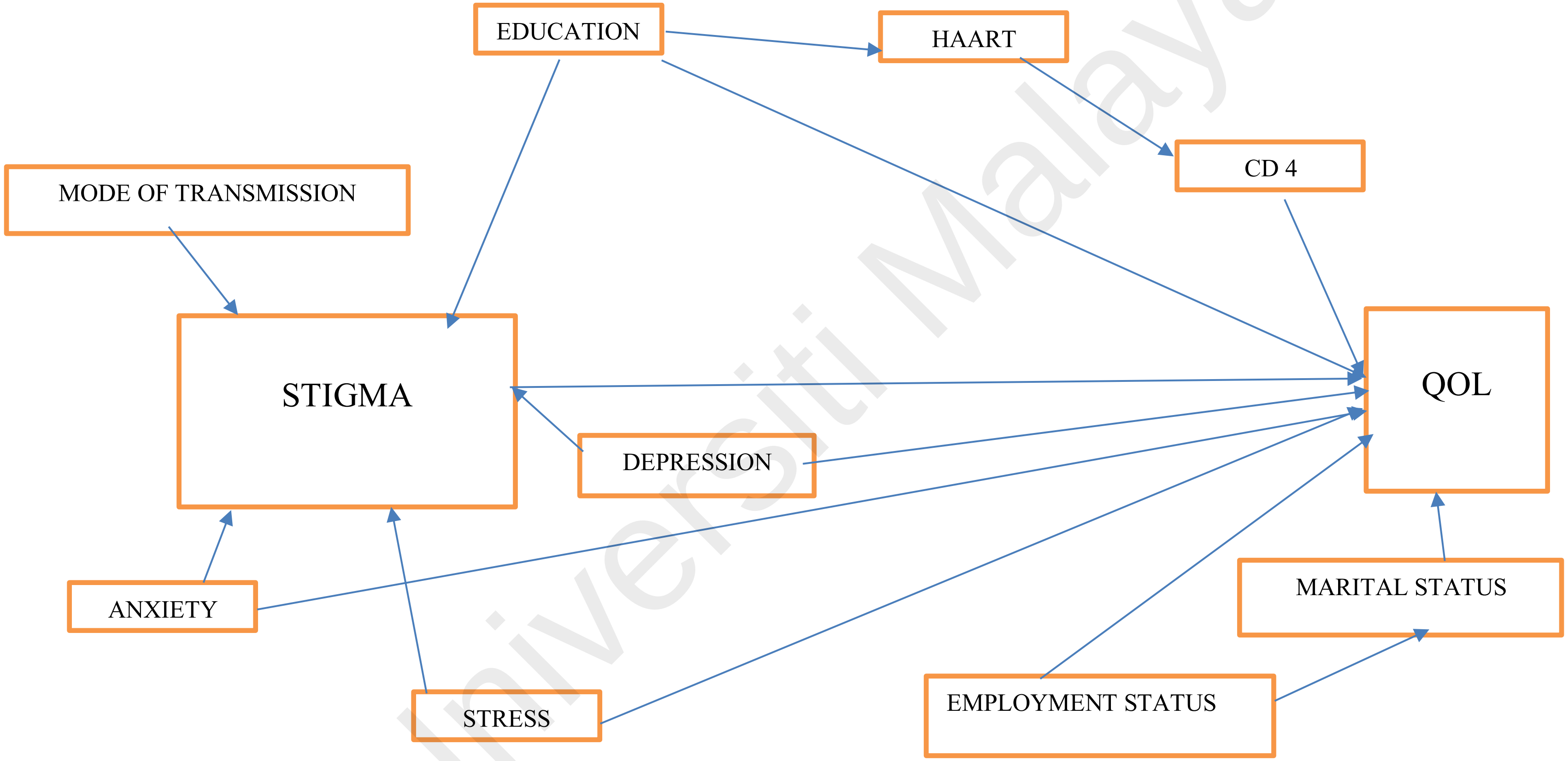


Figure 11: Stigma and quality of life conceptual model

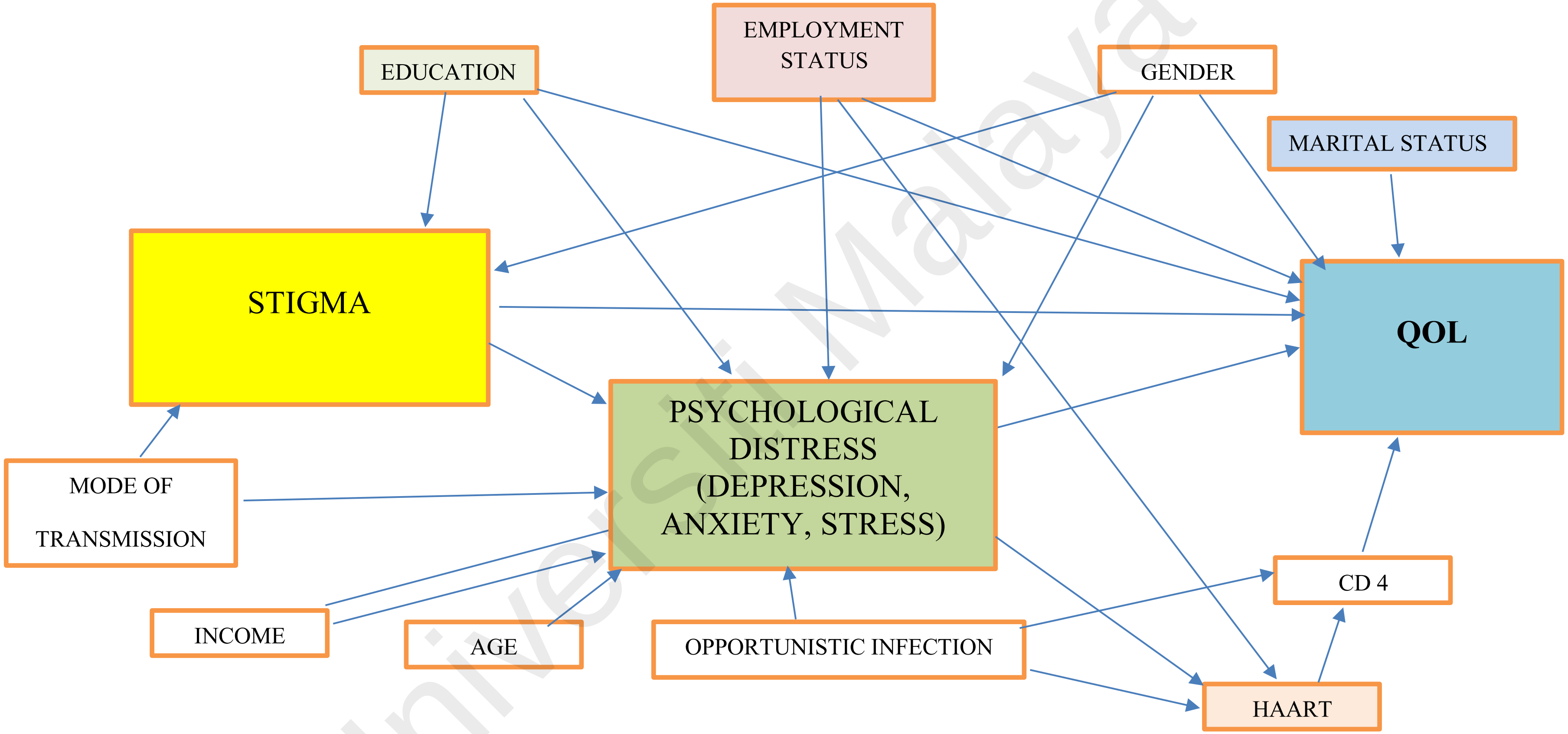


Figure 12: Psychological distress (depression, anxiety and stress), stigma and quality of life conceptual model

CHAPTER 3: METHODOLOGY

3.1 Chapter Overview

This chapter outlines the research methodology of the current study. The research design, target population, sampling technique, research instruments used, and data collection are described. The chapter concludes by describing the ethical considerations of this study.

3.2 Study Design

This is a cross-sectional study involving PLHIV in the Federal Territory of Kuala Lumpur. The study protocol includes the administration of a structured questionnaire and informed consent for primary data collection. Data were collected once from each respondent during the research timeframe. Participation was voluntary after being briefed on the research protocol.

3.3 Area of the Study

This study concentrates on PLHIV in the Federal Territory of Kuala Lumpur. Kuala Lumpur is the federal capital of Malaysia with more than 1.73 million in 2016 in an area of 243-kilometre squares (Department of Statistics, Malaysia, Kuala Lumpur). It is one of the three federal territories with a high population density of 6,890 people per kilometre square. According to the Population and Housing Census of Malaysia, Department of Statistic Malaysia (2010), the ethnic composition in Kuala Lumpur is Malay (40.5 %), Chinese (39.1%), Indian (9.3%) and others (1.6%). The average annual population growth rate in 2015 was 2.4%, with 0.91 million males and 0.87 million females.

3.4 Study Population

The target population of this study included PLHIV on follow up attending the outpatient Infectious Disease Clinic in University Malaya Medical Centre (UMMC) and the Tanglin Health Clinic. Another target population of this study is the PLHIV from the Community-Based Organisation (CBOs) in Kuala Lumpur. The CBOs are "voluntary non-profit making organisations providing HIV/AIDS education, prevention, care and support programmes, sexual health and empowerment programmes for vulnerable communities in Malaysia". Three CBOs in Kuala Lumpur were included in the current study (Ikhlas, PT Foundation and Seed Organisation).

3.5 Case Definitions

i. People living with HIV (PLHIV) is defined as confirmed HIV seropositive patients diagnosed by registered Medical Practitioner and notification made to the Health Office.
ii. PLHIV on follow up is defined as HIV seropositive patients registered to the HIV clinic and having active follow up and treatment.
iii. PLHIV not on follow up is defined as HIV seropositive patients not on any active HIV clinic follow up and treatment.

3.5.1 Inclusion Criteria

The inclusion criteria for PLHIV on follow up will be:

i. Patients with confirmatory serology results, doctor's diagnosis and notification to the District Health Office.
ii. Aged between 18 and 60 years.
iii. A duration of illness for at least six months from the date of illness notification.
iv. Consented to enrol in the study.
v. Registered to HIV clinic UMMC or Tanglin Health Clinic

The inclusion criteria for PLHIV from CBOs will be:

i. PLHIV who has been previously diagnosed as HIV positive from any government or private health facilities.
ii. Ages between 18 and 60 years.
iii. A duration of illness for at least six months from being diagnosed.
iv. Consented to enrol in the study.

3.5.2 Exclusion Criteria for PLHIV on Follow Up and Loss to Follow Up:

i. Paediatrics HIV cases (age less than 18 years).
ii. Patients who refused to give consent to participate in the study.

3.6 Sample Size Calculation

The sample size calculation for this cross-sectional study was calculated using prevalence (Kish, 1965). The formula for sample size calculation using prevalence of depression is 28% based on a study among PLHIV in Infectious Disease Clinic, Hospital Raja Perempuan Zainab II in Kota Bharu Kelantan (Othman et al., 2015):

$$n = (Z_{1-\alpha})^2 * P*(1-P) / D^2)$$

$Z_{\alpha/2}$ is the critical value of the Normal distribution at $\alpha/2 = 1.96$

confidence level = 95%
$\alpha = 0.05$
D is the margin of error=5%
P is the sample proportion= 28%

$$n = (1.96)^2 * 0.28*(1-0.28) / 0.05^2)$$
$$= 3.842 * (0.2016 / 0.0025)$$
$$=310$$

The sample size required for this study is 310 respondents.

3.7 Sampling Method

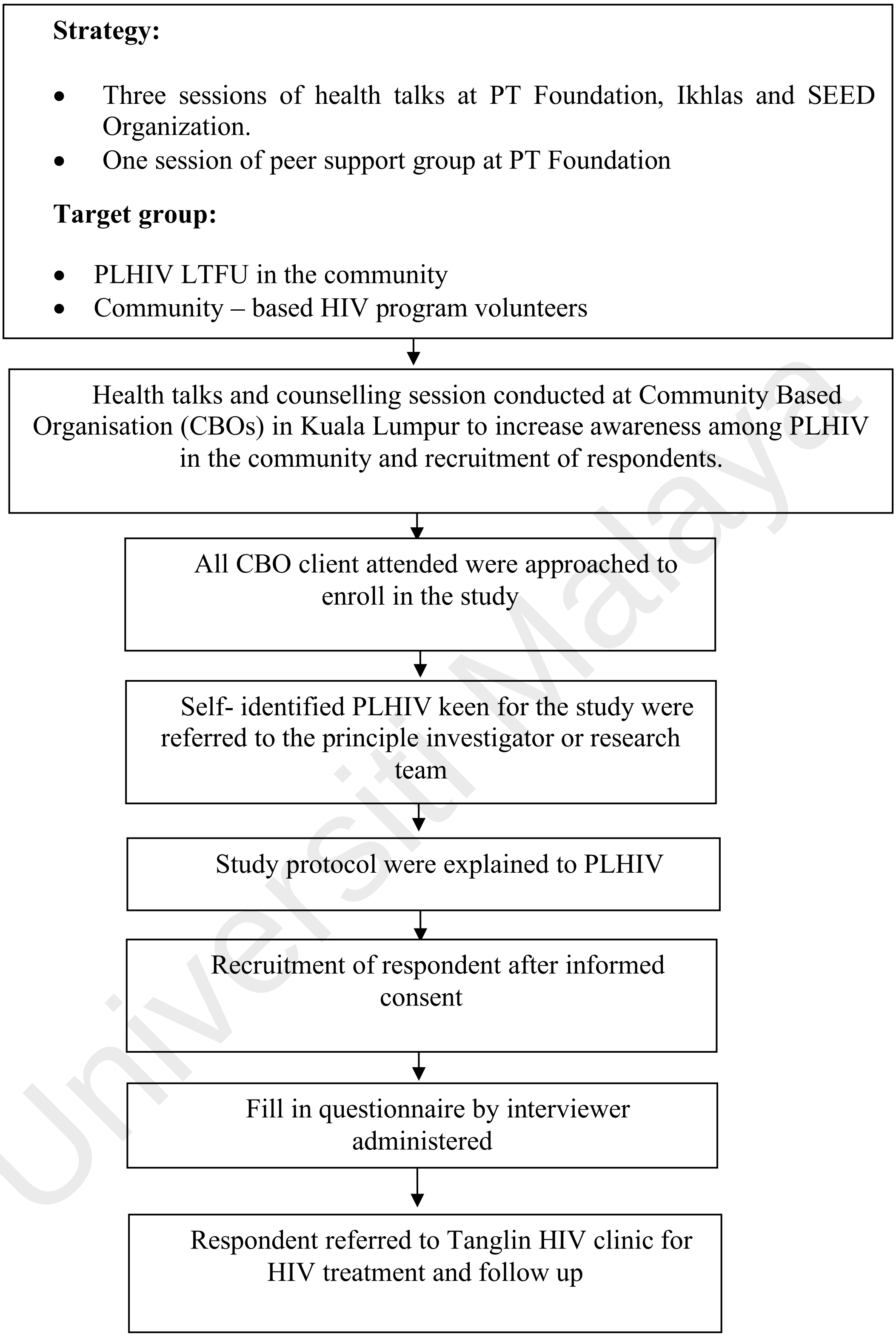
This study used universal sampling of respondents. PLHIV were sampled from HIV clinics and CBOs. All PLHIV attending the clinic sessions and all PLHIV attending health talk at CBOs were approached to participate in the study. Every PLHIV had an equal chance to be involved in the study. Respondents who agreed to enrol in the study were referred to the principle investigator or research team.

3.7.1 Sampling of PLHIV from the UMMC and Tanglin HIV Clinic

The sampling frame for PLHIV on follow up were all HIV patients attending HIV clinic sessions during the data collection period. All HIV patients will be recruited once into the study. During the clinic visits, the attending physician approached HIV patients to enrol in the study. The subjects who agreed to enrol in the study were referred to the principal investigator or the research team. Respondents were briefed regarding the study and were provided with the patient's information sheet. Respondents have the right to refuse to participate in the study, while their rights to receive treatment would not be jeopardised. Written consent was taken and signed by each subject prior to the interview. Respondents answered a set of questionnaires by interview to avoid non-response or missing answers when it was self-administered. Respondent took an average of 20 to 30 minutes to complete the questionnaire. Respondents were given a drink and biscuits as a token of appreciation once they completed the survey.

3.7.2 Sampling of PLHIV from the Community-Based Organisation (CBOs)

Prior to the recruitment of respondents from the CBOs, four health talks were delivered at the CBOs to increase awareness on HIV treatment and follow up. This was done to attract the participation of PLHIV from CBOs to this study and improve the response rate from CBOs. Following the health talks, PLHIV identified themselves to the principle investigator or the research team. Respondents were briefed regarding the study and were provided with the patients' information sheets. Respondents included in the study were those who fulfilled the inclusion and exclusion criteria and consented to enrol in the study. Written informed consent was taken from each respondent. Respondents were given the same set of questionnaires as PLHIV on follow up and administered by face-to-face interview. All respondents were subsequently referred to the Tanglin HIV Clinic located approximately 7 km from the CBOs to resume their treatment and follow up.



Strategy:

- Three sessions of health talks at PT Foundation, Ikhlas and SEED Organization.
- One session of peer support group at PT Foundation

Target group:

- PLHIV LTFU in the community
- Community – based HIV program volunteers

Health talks and counselling session conducted at Community Based Organisation (CBOs) in Kuala Lumpur to increase awareness among PLHIV in the community and recruitment of respondents.

All CBO client attended were approached to enroll in the study

Self- identified PLHIV keen for the study were referred to the principle investigator or research team

Study protocol were explained to PLHIV

Recruitment of respondent after informed consent

Fill in questionnaire by interviewer administered

Respondent referred to Tanglin HIV clinic for HIV treatment and follow up

Figure 13: Flowchart of respondents’ recruitment through community assisted.

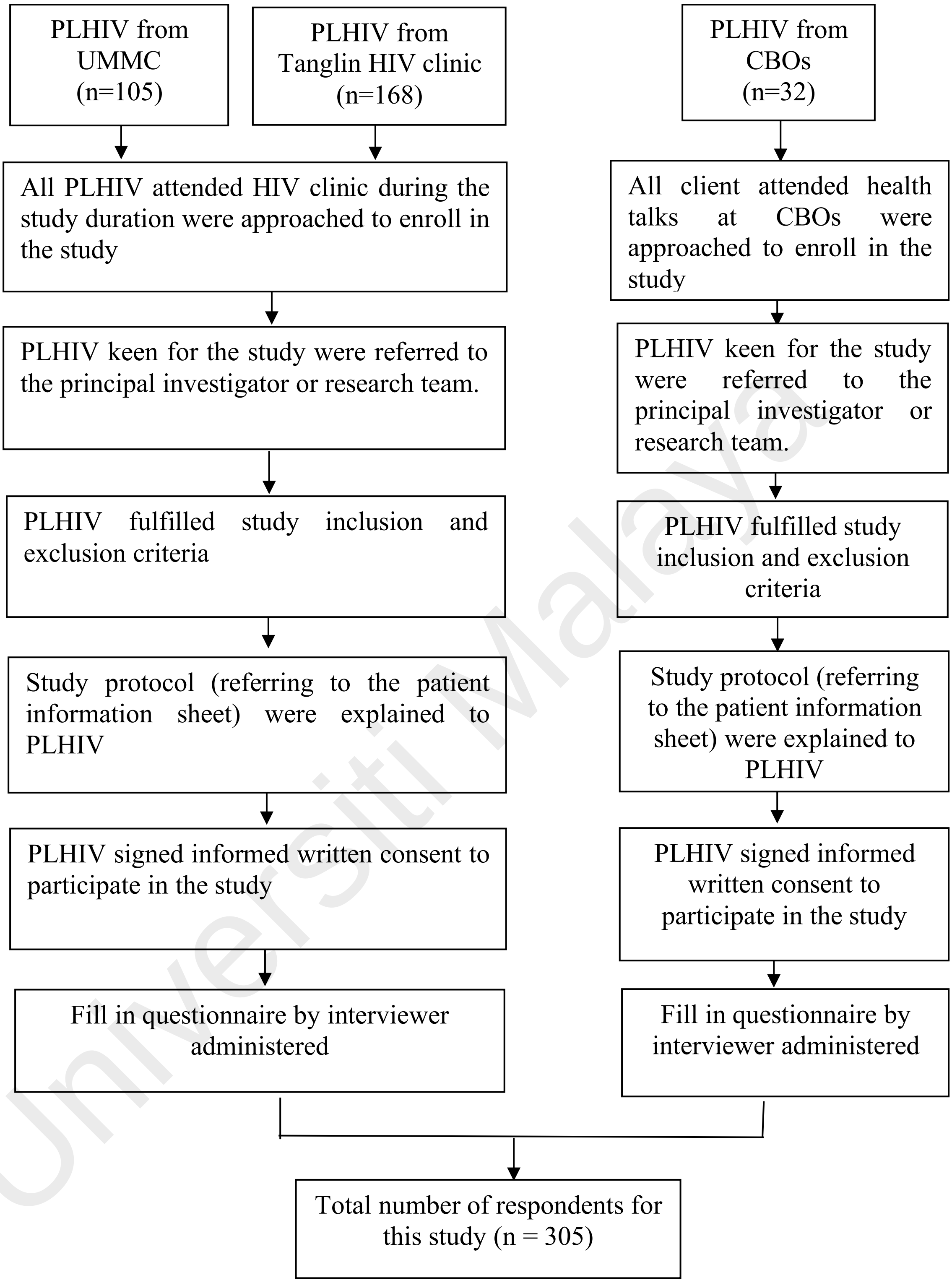


Figure 14: Flowchart sampling technique for PLHIV from UMMC, Tanglin HIV clinic and CBOs

3.8 Study Instruments

Respondents answered a standardised questionnaire which measured the quality of life, psychological distress (depression, anxiety and stress) and perceived stigma among PLHIV. The following are components of the questionnaire:

3.8.1 Clinical and Sociodemographic Variables

Seven sociodemographic variables (gender, age, ethnicity, level of education, marital status, employment status and income) and three clinical variables related to HIV (year diagnosed HIV positive, CD4 level and mode of transmission) were collected in this study.

3.8.2 Definitions of Variables

i. Gender – Respondents were categorised as male and female

ii. Age – The age of the respondents was calculated in the year he/she was born stated on the identification card.

iii. Ethnicity – The ethnic groups were classified as Malay, Chinese, Indian and others. Others include all races apart from the three main races in Malaysia. The Indians and other ethnicity were grouped for data analysis.

iv. Level of education – The education level was documented as the highest attained education level. For the purpose of data analysis, those who reported no formal education and those with primary and secondary education were grouped as non-tertiary level education, while those who obtained education higher than secondary level were grouped as tertiary education.

v. Marital status – Marital statuses were categorised as single, married or divorced. For data analysis purposes, marital status was grouped into married or not married.

vi. Employment status – Employment was categorised as unemployed, part-time and full-time employment. In the data analysis, employment was divided into employed and unemployed.

vii. Income – Income includes salary earned per month categorised into less than RM 1000, between RM 1000 to RM3,000 and above RM 3,000

viii. Year diagnosed HIV – The year respondents was having the positive confirmatory HIV blood test results.

ix. Mode of transmission – Mode of transmission was described as the most predominant risk behaviour which exposes the respondents to get HIV. It was categorised into people who inject drug (PWID), men-sex-men (MSM), heterosexual, needle prick injury, blood transfusion and unknown reason. For purposes of data analysis, blood transfusion, needle prick injury and unknown reason were grouped as another mode of transmission.

3.8.3 WHOQOL-HIV BREF Malay version

The World Health Organisation Quality of Life: HIV Brief version (WHOQOL-HIV BREF) has six domains, namely physical domain, psychological domain, level of independence domain, social relationship domain, environment and spirituality/religion/personal beliefs domain. It contains 31 items representing 30 facets, with five facets specific to HIV/AIDS (Pedroso et al., 2011). The WHOQOL-HIV BREF is based on the WHOQOL-BREF, which is a shorter version of WHOQOL 100. Questions 1 and 2 examine the general QOL by the individual's overall perception of the quality of life and overall perceptions of his or her health. Questions related to symptoms of PLHIV include forgiveness and blame, concerns about future and death and question about dying. Every item was rated with a 5-point Likert scale with responses ranging from 1 to 5, where one indicates low negative perceptions and five indicates a high score with positive perceptions. The WHOQOL-100 Malay version pilot study was undertaken by Hasanah & Razali (1999) without the additional five item in the WHOQOL-HIV BREF and the Malay version WHOQOL-HIV BREF was validated by Saddki et al. (2009).

3.8.4 Depression Anxiety Stress Scale 21-item (DASS-21)

DASS is a self-report questionnaire that measures depression, anxiety and stress. The original version of DASS has 42-items while the current study uses the DASS 21-item, which is the shorter version. The tool is non-diagnostic, but it measures severity. It is suitable for normal adolescent and adult population. It may be administered and scored by non-psychologist. The depression scale assesses symptoms related to depressive mood like hopelessness, lack of interest, dysphoria and devaluation of life. The anxiety scale assesses symptoms related to anxiety disorder like situational anxiety, the experience of anxious affect and autonomic arousal. The Malay version of DASS-21 has been validated, and it is found to be a suitable research tool for Malaysia (Musa, Fadzil, & Zain, 2007). The same classification of the severity of depression, anxiety and stress were used in the local context as described below.

Scores for the DASS were calculated by summing scores for the relevant items and converting them into percentile scores. Based on the percentiles cut-off, respondents scoring less than the 78th percentile were considered as normal; scores between the 78-87th percentiles were considered as mild; and scores between the 85-95th percentiles were moderate and those with scores between the 95-98th percentiles were having severe, and extremely severe for those with scores between 98-100 percentiles (Abdin Edimansyah et al., 2008).

The 21-item DASS was used to assess the current state of depression, anxiety and stress symptoms, and it was especially well-suited for the assessment of this condition since it minimised the amount of overlap. The depression scale included seven items that measured dysphoric mode symptoms, for example "I felt that life was meaningless, and I felt sad and depressed". The anxiety scale measured symptoms of physical arousal, panic attack and fear for example "I felt I was close to panic" and "I felt scared without any good reason" The stress scale measured symptoms such as tension "I found it difficult to relax" and "I felt that I was using a lot of nervous energy". Every item was rated with a 4-point severity scale with response ranging from 1 to 4. Respondents were asked to rate the severity of symptoms they experienced over the past week. Table 3.1 showed general guidelines for the Depression Anxiety Stress Scale -21 severity rating.

Table 3.1: General guidelines for the Depression Anxiety Stress Scale-21 severity rating

Severity rating	Percentile	DASS-Depression	DASS-Anxiety	DASS - Stress
Normal	0-78	0-4	0-3	0-7
Mild	78-87	5-6	4-5	8-9
Moderate	87-95	7-10	6-7	10-12
Severe	95-98	11-13	8-9	13-16
Extremely Severe	98-100	14+	10+	17+

Reference: Lovibond & Lovibond (1995)

In the current study, depression scale, anxiety scale and stress scale were classified as severe and not severe, according to the 87th percentile cut-off value. This categorisation is exclusive to this study.

3.8.5 HIV Stigma Scale

The respondents' perceived stigma on HIV was assessed using the HIV Stigma Scale. The possible scores of this scale ranged from 40 to 160. The higher scores indicate a higher degree of perceived stigma and lower scores indicate a lower degree of perceived stigma. The questionnaire measures four domains of HIV-related stigma:

a) Personalised stigma is the stigma that arises as the consequences of others knowing the HIV status, or it means the individual perceived that PLHIV are rejected when others know their positive status.

b) Disclosure concerns are stigma related to the fear of disclosing one's HIV status due to the fear that those who know will inform others. PLHIV were very concerned on controlling whom to tell and whom not to tell.

c) A negative self-image is a stigma experienced by PLHIV where they perceived themselves as tainted and not as good as others because they were living with HIV. It consists of items related to feelings of isolation, shame and guilt once been diagnosed with HIV infection.

d) Perceived public attitude concerns public attitude and perceptions of what people might think about a person with HIV. The perceptions of the public's attitude towards PLHIV contribute to the impact of stigma and discrimination towards PLHIV.

There were 40 items rated with a 4-point Likert scale with one indicating “strongly disagree” with the statement and four indicating “strongly agree”. Higher scores indicate higher levels of stigma and lower scores indicate lower levels of stigma. Based on four forms of stigma, it is reported to have good construct validity and consistent internal reliabilities with coefficient alpha between 0.90 and 0.93 for each subscale. The Malay translated version of the HIV stigma scale has been used in other studies in Malaysia (Choi et al., 2010; Fadzil & Zahiruddin Othman, 2016; and Othman et al., 2015).

There is no specific score grading or classification for the HIV stigma scale. The total HIV Stigma was the sum of each of the 40 items in the total scale, and it could not be calculated simply by adding up the four subscale scores (Berger, Ferrans, & Lashley, 2001). The reverse code was applied for item “I never feel ashamed of having HIV” and” I never feel the need to hide the fact that I have HIV”. After reversing, the score of each scale or subscale is calculated by simply adding the values of the item belonging to the scale. Total HIV stigma score range from 40 to 160 and personalised stigma subscale score ranges from 18 to 72; disclosure subscale ranges from 10 to 40, negative self-image subscale ranges between 13 to 52 and public attitude subscales ranges from 20 to 80. The total HIV stigma score was the sum of the 40 items of the Berger scale.

3.9 Validity and Reliability of the Study Instrument

The Depression Anxiety Stress Scale (DASS) has been translated into many different languages and validated in many populations worldwide. The DASS-21 has been translated into Bahasa Malaysia by Musa et al. (2007). A validity study of Malay version DASS-21 showed very good Cronbach alpha values of 0.84 for depression, 0.74 for anxiety and 0.79 for stress. The Malay version DASS-21 has been validated among Malaysian diabetic patients (Ramli, Salmiah, & Nurul Ain, 2009) and also among male automotive assembly workers in Malaysia (Abdin Edimansyah, Nordin Rusli, Lin Naing, Abdullah Mohamed Rusli, 2008) with very good Cronbach's alpha values of 0.75 for depression, 0.74 for anxiety and 0.79 for stress.

The validation study of the Malay version of WHOQOL-HIV-BREF was done among 157 PLHIV at Infectious Disease Unit, Hospital Raja Perempuan Zainab II, Kota Bharu, Kelantan with good validity and reliability by Saddki et al. (2009). The internal consistency of all five domains was good ranging from 0.70 to 0.83, and the intraclass correlation coefficient was high ranged from 0.6 to 0.87 across all five domains.

3.10 Pilot Testing

Pilot studies were conducted in the clinic setting and CBOs prior to the actual study to test the clarity and reliability of the questionnaire and feasibility of the study. The research instrument was piloted with PLHIV in the Infectious Disease Clinic in Hospital Sungei Buloh. A second pilot study was conducted among residents of HIV shelter home named Istana Budi in Selangor. Data were collected from 25 respondents who fulfilled the study criteria from May to June 2014. Respondents were conveniently selected with 17 respondents from Infectious Disease Clinic Hospital Sungei Buloh and eight respondents from the shelter home. Participants of this pilot study were excluded from the main study and data obtained were not included in the final data analysis of the main study. The pilot study was used to familiarise the researcher with the questionnaire and to test the appropriateness and clarity of the questions. It also provides information on the estimated time required to complete the surveys, gives comments and feedback from the participants and resulted in a minor adjustment to the sentence structure in the sociodemographic section. All other sections of the survey remained unchanged. This pilot testing had no bearing on the internal validity of the questionnaire. The final version of the instruments is shown in the Appendix. The pilot test respondents' demographic characteristics are shown in Table 3.2.

Table 3.2: Sociodemographic characteristics of pilot study respondents (N=25)

Variables	Mean ± SD or n (%)
Gender	
Male	21 (84%)
Female	4 (16%)
Age (Years)	43.24 ± 9.3
Education Level	
Primary/ secondary level	23 (92%)
Tertiary level	2 (8%)
Marital Status	
Married	4 (16%)
Unmarried	21 (84%)
Employment Status	
Employed	6 (24%)
Unemployed	19 (76%)
Mode of Transmission	
MSM	4 (16%)
Heterosexual	4 (16%)
Injecting drug user	15 (60%)
Others	2 (8%)
Current HAART Treatment	
Yes	19 (76%)
No	6 (24%)

3.11 Ethical Considerations

Ethics clearance for this study was obtained from the University of Malaya Medical Centre's Research Ethics Committee (MECID 201312-0595) and the National Medical Research Registry (NMRR-13-1466-17832). Ethical issues observed in this study include informed consent, the right for confidentiality, right to privacy, justice and respect for persons as described below.

3.11.1 Permission to Conduct the Study

Permission to conduct the study was obtained to collect data from PLHIV attendees of the HIV clinic in University Malaya Medical Centre, Tanglin Health Clinic and CBOs in Kuala Lumpur.

3.11.2 Respect for the Persons as Autonomous Individuals

The current study seeks to assess the level of QOL, mental health status and perceived stigma among PLHIV. Respondents have the right to choose to participate in the research autonomously. The decision to participate is made without any coercion. The study purpose was fully explained to respondents in the language they understand. The risks and benefits of the study were also highlighted. Respondents were informed that they were free to withdraw and refusal to participate would not affect the health services to which they are entitled. Prior to signing the consent, participants were given time to ask questions to ensure their full understanding. Finally, respondents were asked to sign a standardised written consent as an agreement to enrol in the study.

3.11.3 Confidentiality and Anonymity

The privacy and anonymity of respondents are paramount. To ensure the anonymity of respondents, names and personal identity of the individuals such as personal characteristics, workplace and occupation were not revealed when presenting the results so that researcher would not be able to link information in the questionnaire to any specific respondents. To protect the confidentiality of information given by respondents, the interview session was conducted in a private room where no third person could hear the interview session.

3.11.4 Avoiding Harm

In this study, probable risks the patient could encounter include psychological and emotional harm through long waiting periods and in maintaining the confidentiality and anonymity of the respondent. The researcher was able to reduce the possible psychological harm by and to ensure privacy, anonymity and confidentiality of respondent and maintaining respects throughout the interview sessions.

3.11.5 Justice

Participants in this study were treated fairly by giving information prior to participation, and they were given the options to withdraw from the study without jeopardising their entitlement to health services. The selection of respondents, according to the guidelines ensured that all respondents meet the selection criteria and are given a fair chance to be selected to enrol in the study.

3.11.6 Informed Consent

All respondents in this study were given a comprehensive explanation of the study. Following that, respondents were required to sign a written consent form as an agreement to enrol in the study.

3.11.7 Distress to participants

Respondents showed signs and symptoms of distress during the interview, respondents with abnormal (mild and moderate to extremely severe) depression, anxiety and stress score were all referred to HIV counsellor in UMMC HIV clinic and Tanglin HIV clinic for further mental health management.

3.12 Data Analysis

The Statistical Package for Social Sciences (SPSS) version 19 was used to analyse the data to answer the research objectives. Prior to the data analysis, preliminary analyses were conducted to inspect for violation of the following assumptions: assumptions of linearity, homogeneity of regression slope, assumptions of homoscedasticity and homogeneity of variance. The analyses found that visual inspection of the scatter plot showed a linear relationship between QOL and covariates of independent variables.

Data were analysed for normality, central tendency and variability. Continuous variables were expressed as mean (SD) or median (interquartile range). Categorical variables were reported as number and proportion. Normally distributed continuous variables were analysed using the independent t-test and one-way analysis of variance (ANOVA). Categorical variables were analysed by Chi-square analysis or Fisher exact test.

Categorical variables were analysed using descriptive univariate statistics consisting of frequencies and percentages. Scale and index variables which were treated as continuous variables were analysed using means and standard deviation (SD). Bivariate associations between QOL and continuous variables were assessed via Pearson's correlation coefficients. The difference in means between categories of dichotomous variables was assessed via the t-test.

Variables with a significant association with $p<0.05$ in the analyses were subsequently entered into a multiple linear regression model. No evidence of multicollinearity was found between the independent variables with all VIF and tolerance values were <2.5 and >0.40, respectively. Residuals were examined for non-normality, heteroscedasticity and influential outliers (via Cook's distance D) and does not seem to be problematic. All statistical test was two-tailed, and *p*-value of less than 0.05 was taken as statistically significant.

3.13 Conclusion

This chapter described in detail the methodology of the current study designed to answer the study objectives. It includes the sampling method for PLHIV from the HIV clinic setting and sampling from the Community Based Organisation. The chapter also described the basis of study instruments selection to measure quality of life, psychological distress and stigma among PLHIV. The important ethical considerations of the study were also explained.

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CHAPTER 4: RESULTS

4.1 Chapter Overview

This chapter presents the detailed results of the data analysis. The first part describes the characteristics of the respondents. This is followed by comparing the baseline characteristics of respondents between survey centres. The QOL of respondents and its association with psychological distress and stigma is also examined.

4.2 Data Collection and Response Rate

A total of 305 respondents was enrolled in this study. The study participants comprised of 105 respondents from UMMC, 168 respondents from Tanglin Health Clinic and 32 respondents from CBOs. According to the sample size calculation, the required sample size for this study is 310 respondents. However, we managed to enrol only 305 respondents (98.4%).

Table 4-1: Response rate of respondents enrolled in the study by survey centres

Activities	Survey Centre		
	UMMC n (%)	Tanglin HIV Clinic n (%)	CBOs n (%)
HIV registered patients during the study period	720	960	32
Agreed and consented	105 (14.5%)	168 (17.5%)	32(100%)

4.2.1 Response Rate by Survey Centres

Data were collected in UMMC from January until March 2014. There were 720 HIV clinic attendees in UMMC during the data collection period. The study enrolled 105 respondents with a response rate of 14.5%. Data collection at Tanglin HIV Clinic was from February until August 2015. A total of 960 respondents visited Tanglin HIV Clinic during the data collection period. The response rate for Tanglin respondents was 17.5% with 168 respondents agreeing to participate in the study.

Recruitment of PLHIV at the CBOs was conducted from February until August 2015. Thirty-two respondents self-identified as PLHIV, and they agreed to enrol in this study with 100% response rate. All 32 respondents from CBOs were LTFU from HIV clinic more than 6 months.

4.3 Characteristics of the Study Participants

4.3.2 Sociodemographic Characteristics of PLHIV (N=305)

The sociodemographic characteristics of respondents of the current study are shown in Table 4.2. The mean age of respondents was 37.9 ± 9.8, range 18 to 71 years. The respondents' longest duration of living with HIV was 24 years, with two respondents who were diagnosed in 1991. The mean time elapsed since they knew they were positive for HIV was seven years. The majority of respondents were male (91.8%, n=280), had either no formal, primary or secondary education (61%, n = 186). This study had more respondents who were unmarried (80%, n = 244) and employed (68.2%, n = 208). Malay respondents represented about 64.9%, followed by Chinese 22% and Indian / other ethnic groups 13%.

4.3.3 HIV-related Variables of PLHIV (N=305)

The majority (34%, n = 111) of the respondents were men having sex with men (MSM), followed by PWID (29.2%, n = 80) and heterosexuals (26.2%, n = 89). Sexual risk behaviour contributes to 70% (n = 191) of the mode of transmission, while 29.2% (n = 89) were sharing needles and 3.9% (n = 12) identified blood products and needle pricks as a mode of transmission. Two (1%) respondents answered: "I don't know how I got HIV infection". The majority (70.5%, n = 215) of the respondents were on HAART.

Table 4-2: Sociodemographic characteristics and HIV-related variables of the respondents

Variables	Mean ± SD or n (%)
Age (Years)	37.9 ± 9.8
Gender	
Male	280 (92%)
Female	25 (8%)
Ethnicity	
Malay	198 (65%)
Chinese	67 (22%)
Indian / others	40 (13%)
Education Level	
No tertiary	186 (61%)
Tertiary	119 (39%)
Marital Status	
Married	61 (20%)
Unmarried	244 (80%)
Employment Status	
Employed	208 (68.2%)
Unemployed	97 (31.8%)
Income	
Low income	186 (61%)
Medium income	60 (19.7%)
High income	59 (19.3%)
Mode of Transmission	
MSM	111 (36.4%)
Heterosexual	80 (26.2%)
PWID	89 (29.2%)
Others	25 (8.2%)

*MSM (men-sex-men), PWID (people who inject drug).

Table 4.2: Sociodemographic characteristics and HIV-related variables of the respondents. (Continued)

Variables	Mean ± SD or n (%)
Opportunistic Infection	
Yes	130 (42.6%)
No	175 (57.4%)
CD4 Level	394.06 ± 264.26
Current HAART	
Yes	215 (70.5%)
No	90 (29.5%)
NGO Support	
Yes	48 (15.7)
No	257 (84.3)

* HAART (highly active antiretroviral treatment).

4.4 Characteristics of Participants by Survey Centres

This study sampled three survey centres, namely an HIV clinic in a hospital setting, UMMC (n=105), Tanglin HIV Clinic in a primary healthcare setting (n=168) and Community Organisation (CBOs)(n=32).

4.4.1 Sociodemographic Characteristics and HIV-related Variables of PLHIV Between Survey Centres (N=305)

Table 4.3 presents the sociodemographic characteristics of respondents according to survey centres. There were significant differences between ethnicity, education level, and employment status of respondents between survey centres. Respondents from the University Malaya Medical Centre (UMMC) were majority male (92.4%, n = 155), Malay (44.8%, n = 47), being unmarried (24.8%, n = 26) with tertiary education (57.1%, n = 60) and employed (7.9%, n = 24). The Tanglin HIV Clinic respondents were majority male (92.3%, n = 155), Malay (73.8%, n = 124), unmarried (81.5%, n = 137) with no formal or primary and secondary education (66.7%, n = 112) and employed (66.7%, n = 112). The majority of PLHIV respondents who were loss to follow up (LTFU) from CBOs were male (87.5%, n = 28), of Malay (84.4%, n = 27), unmarried (87.5%, n = 28) with no formal or primary and secondary education (90.6%, n = 29) and unemployed (84.4%, n = 27).

The mean age of UMMC respondents was 37.4 years ± 9.9, Tanglin HIV Clinic respondents were 37.48 years ± 9.7, and CBOs respondents was 41.78 years ± 9.1. The mean age difference between these groups was statistically significant ($p = 0.006$). The majority (86.7%, n = 91) of respondents from UMMC and (72.6%, n = 122) Tanglin HIV Clinic were on HAART treatment while the majority (93.8%, n = 30) of CBOs respondents were never put on HAART and only 6.2% were started on HAART before they LTFU from the HIV clinic.

Table 4-3: Sociodemographic characteristics and HIV-related variables stratified by survey centres

		Survey Centres			
Characteristics	**Total**	**UMMC n = 105**	**Tanglin HIV Clinics n = 168**	**CBOs n = 32**	
	n (%)	n (%)	n (%)	n (%)	**p-value**
Age (mean ± SD)		37.39 ± 9.9	37.48 ± 9.7	41.78 ± 9.1	0.060
Gender					0.644
Male	280 (91.8%)	97 (92.4%)	155 (92.3%)	28 (87.5%)	
Female	25 (8.2%)	8 (7.6%)	13 (7.7%)	4 (12.5%)	
Ethnicity					<0.001
Malay	198 (64.9%)	47 (44.8%)	124 (73.8%)	27 (84.4%)	
Chinese	67 (22.0%)	38 (36.2%)	25 (14.8%)	4 (12.5%)	
Others	40 (13.1%)	20 (19.0%)	19 (11.3%)	1 (3.1%)	
Education Level					<0.001
No tertiary	186 (61.0%)	45 (42.9%)	113 (66.8%)	28 (87.5%)	
Tertiary	119 (39.0%)	60 (57.1%)	55 (32.7%)	4 (12.5%)	
Marital Status					0.239
Married	61 (20.0%)	26 (24.8%)	31 (18.5%)	4 (12.5%)	
Unmarried	244 (80.0%)	79 (75.2%)	137 (81.5%)	28 (87.5%)	
Employment Status					<0.001
Employed	208 (68.2%)	90 (85.7%)	113 (67.3%)	5 (15.6%)	
Unemployed	97 (31.8%)	15 (14.3%)	55 (32.7%)	27 (84.4%)	
Income					<0.001
Low income	186 (61.0%)	34 (32.4%)	122 (72.6%)	30 (93.8%)	
Medium income	60 (19.7%)	36 (34.3%)	23 (13.7%)	1 (3.1%)	
High income	59 (19.3%)	35 (33.3%)	23 (13.7%)	1 (3.1%)	
Mode of Transmission					<0.001
MSM	111 (36.4%)	54 (51.4%)	55 (32.7%)	2 (6.3%)	
Heterosexual	80 (26.2%)	38 (36.2%)	37 (22.0%)	5 (15.6%)	
PWID	89 (29.2%)	4 (3.8%)	62 (36.9%)	23 (71.9%)	
Others	25 (8.2%)	9 (8.6%)	14 (8.3%)	2 (6.3%)	
Opportunistic infection					<0.001
Yes	130 (42.6%)	28 (26.7%)	83 (49.4%)	19 (59.4%)	
No	175 (57.4%)	77 (73.3%)	85 (50.6%)	13 (40.6%)	
Current HAART Treatment					<0.001
Yes	215 (70.5%)	91 (86.7%)	122 (72.6%)	2 (6.3%)	
No	90 (29.5%)	14 (13.3%)	46 (27.4%)	30 (93.8%)	
NGO Support					0.501
Yes	48 (15.7%)	14 (13.3%)	27 (16.1%)	7 (21.9%)	
No	257 (84.3%)	91 (86.7%)	141 (83.9%)	25 (78.1%)	

*MSM (men-sex-men), PWID (people who inject drug), HAART (highly active antiretroviral treatment).

Table 4.4 describes the distribution of total QOL and QOL domains scores according to survey centres. The mean total QOL score was significantly higher in UMMC (97.4 ± 14.2), and Tanglin (93.9 ± 14.4) compared to CBOs (80.1 ± 18.4) respondents ($p<0.05$). The mean scores of CBOs respondents were lowest, and UMMC respondents were highest among the three centres for all QOL domains.

Table 4-4: Mean quality of life domain score according to survey centres

Quality of Life Domain	**Survey Centres**			**p-value**
	UMMC (n = 105)	**Tanglin Clinic (n = 168)**	**CBOs (n = 32)**	
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	
Total QOL	**97.4 ± 14.2**	**93.9 ± 14.4**	**80.2 ± 18.4**	< 0.001
Physical Domain	13.9 ± 2.8	13.8 ± 3.1	11.9 ± 3.3	0.002
Psychological Domain	14.1 ± 2.8	13.9 ± 2.5	12.1 ± 2.7	< 0.001
Level of Independence Domain	14.1 ± 2.3	13.4 ± 2.2	11.8 ± 2.7	< 0.001
Social Relationship Domain	13.7 ± 3.0	12.9 ± 3.1	10.9 ± 3.5	< 0.001
Environment Domain	14.2 ± 2.4	13.6 ± 2.7	10.9 ± 3.3	< 0.001
Spirituality /Religion/Personal Belief Domain	12.9 ± 2.3	12.2 ± 2.3	11.7 ± 2.9	0.019

4.5 Quality of Life Among PLHIV

The mean score for total quality of life was 93.7 ± 15.6, ranging from 41.5 to 135.5. There were six quality of life domains and general QOL domain in the WHOQOL-HIV Brief. Referring to data in Table 4.5, the highest domain score was reported for the psychological domain (mean score 13.8 ± 2.7, followed by the physical domain (mean score 13.7 ± 3.1) and environment domain (mean score 13.5 ± 2.8). The lowest domain score was for social relationship domain (mean score 12.9 ± 3.2) and spirituality/ religion/ personal belief domain (mean score 12.4 ± 2.4). The overall quality of life mean score was 13.9 ± 3.1.

Table 4-5: WHOQOL-HIV BREF domain mean score

Variables	Mean ± SD	Median	Min-Max
Total QOL	**93.7 ± 15.6**	**94.3**	**41.5-135.5**
Physical domain	13.7 ± 3.1	14.0	6-20
Psychological domain	13.8 ± 2.7	13.6	4-20
Level of independence domain	13.5 ± 2.4	14.0	7-20
Social relationship domain	12.9 ± 3.2	13.0	4-20
Environment domain	13.5 ± 2.8	13.5	5.5-20
Spirituality / Religion/ Personal Belief domain	12.4 ± 2.4	12.0	6-18
Overall general health perception	13.9 ± 3.1	14.0	4-20

Total respondents = 305

4.5.1 Total QOL Score

Table 4.6 and 4.7 presented the mean score of the QOL domain by sociodemographic characteristics. Education level, marital status, employment status, the mode of transmission, current HAART therapy and opportunistic infection were significantly associated with total QOL (p < 0.05). There was no significant association between gender and ethnicity with total QOL score p>0.05. Respondents with tertiary education were having a higher mean total QOL score (99.0 ± 14.1) compared to those without tertiary education (mean score 90.2 ± 15.5). Higher mean total QOL score was found among married respondents (mean score 98.8 ± 15.9) and those who were employed (mean score 97.8 ± 13.1). Respondents on HAART treatment and no opportunistic infection have higher mean total QOL score (mean score 96.4 ± 14.4 and 97.5 ± 13.5) respectively p<0.005. People who inject drugs (PWID) have significantly lower total QOL mean score (84.5 ± 15.7) compared to MSM (mean score 97.5 ± 14.6) and heterosexuals (mean score 96.8 ± 13.6), p<0.001.

a) Physical Domain

The mean score achieved by respondents with tertiary education (mean score 14.6 ± 2.6) were significantly higher than those achieved by respondents with non-tertiary education (mean score 13.4 ± 3.2,) with p = 0.03. Respondents who were married (mean score 14.5 ± 3.3), employed (mean score 14.2 ± 2.8), having heterosexual transmission as risk factor (mean score 14.6 ± 2.8), on HAART treatment (mean score 14.1 ± 3.0) and no opportunistic infection (mean score 14.3 ± 2.8) had a significantly higher mean score in physical domain ($p< 0.05$).

b) Psychological Domain

The psychological domain mean score was significant in relation to the education level, marital status, employment status, mode of transmission, HAART treatment and opportunistic infection with $p<0.05$. There was a higher mean score among those who with tertiary education (mean score 14.6 ± 2.6), married (mean score 14.5 ± 2.8), employed (mean score 14.3 ± 2.5) on HAART treatment (mean score 14.2 ± 2.6) and no opportunistic infection (mean score 14.3 ± 2.5). PWID had the lowest mean score for the psychological domain (mean score 12.5 ± 2.6).

c) Level of Independence Domain

Mean score for level of independence domain was also significant in relation to education level, marital status, employment status and mode of transmission, HAART treatment and opportunistic infection with $p<0.05$. There was a higher mean score among those with tertiary education (mean score 14.2 ± 2.4), married (mean score 14.0 ± 2.5) employed (mean score 14.1 ± 2.1) on HAART treatment (mean score 13.9 ± 2.3) and no opportunistic infection (mean score 13.9 ± 2.2). Respondents with other mode of transmission scored higher in this domain (blood transfusion, needle prick injury).

d) Social Relationship Domain

The social relationship domain mean score was significant in relation to education level, marital status, employment status, mode of transmission, HAART treatment and opportunistic infection with $p<0.05$. Those respondents with tertiary education (mean score 13.9 ± 3.2), married (mean score 14.1 ± 3.3), employed (mean score 13.6 ± 2.8), on HAART treatment (mean score 13.2 ± 3.1) and no opportunistic infection (mean score 13.6 ± 2.9) had a higher mean score in this domain ($p< 0.05$).

e) Environment Domain

The mean score for this domain was significant in education level, marital status, employment status, mode of transmission, HAART treatment and opportunistic infection with $p<0.05$. There was a higher mean score among those with tertiary education (mean score 14.9 ± 2.3), married (mean score 14.2 ± 2.6) employed (mean score 14.3 ± 2.3), having MSM as mode of transmission (mean score 14.7 ± 2.4) on HAART treatment (mean score 13.9 ± 2.5) and no opportunistic infection (mean score 13.6 ± 2.9).

f) Spirituality / Religion/ Personal Belief Domain (SRPB)

In the spiritual domain, the Chinese scored higher than other ethnic groups (mean score 13.4 ± 1.9). Education level and marital status were not significant in this domain with $p= 0.82$ and $p=0.29$, respectively. The mean score for spirituality / religion / personal domain was significant for employment status and mode of transmission, HAART treatment and opportunistic infection with $p<0.05$. Respondents who were employed, on HAART treatment and no opportunistic infection, had a significantly higher mean score in the environment domain (mean score 12.6 ± 2.2) (mean score 12.6 ± 2.3) and (mean score 12.7 ± 2.2) respectively.

g) Overall QOL and General Health Perception

The mean score for overall QOL was significant in education level, marital status, employment status, mode of transmission, HAART treatment and opportunistic infection with $p<0.05$. There was a higher mean score among those with tertiary education (mean score 14.6 ± 2.7), married (mean score 14.8 ± 3.1), employed (mean score 14.6 ± 2.7), on HAART treatment (mean score 14.4 ± 2.7) and no opportunistic infection (mean score 14.4 ± 2.8).

Table 4-6 : Distribution of sociodemographic characteristics and HIV-related variables with total QOL, physical, psychological and level of independence mean score domain

Variables	Total QOL Mean ± SD	p-value	Physical Mean ± SD	p-value	Psychological Mean ± SD	p-value	Level of independence Mean ± SD	p-value
Gender		0.655		0.622		0.665		0.839
Male	93.5 ± 15.6		13.7 ± 3.1		13.8 ± 2.7		13.5 ± 2.4	
Female	94.9 ± 15.1		14.0 ± 3.2		14.0 ± 2.6		13.4 ± 2.2	
Ethnicity		0.481		0.29		0.957		0.887
Malay	92.9 ± 16.5		13.5 ± 3.1		13.8 ± 2.8		13.4 ± 2.4	
Chinese	95.5 ± 12.5		13.9 ± 2.8		13.9 ± 2.3		13.6 ± 2.3	
Indian/others	94.4 ± 15.3		14.2 ± 3.5		13.8 ± 2.8		13.4 ± 2.7	
Education Level		<0.001		0.028		<0.001		<0.001
No tertiary	99.0 ± 14.1		14.2 ± 2.8		14.6 ± 2.6		14.2 ± 2.4	
Tertiary	90.2 ± 15.5		13.4 ± 3.2		13.3 ± 2.7		12.9 ± 2.2	
Marital Status		0.004		0.029		0.021		0.033
Unmarried	92.4 ± 15.3		13.5 ± 2.9		13.6 ± 2.6		13.3 ± 2.3	
Married	98.8 ± 15.9		14.5 ± 3.3		14.5 ± 2.8		14.0 ± 2.5	
Employment Status		<0.001		<0.001		<0.001		<0.001
Employed	97.8 ± 13.1		14.2 ± 2.8		14.3 ± 2.5		14.1 ± 2.1	
Unemployed	84.4 ± 16.5		12.5 ± 3.4		12.6 ± 2.9		12.1 ± 2.3	
Mode of Transmission		<0.001		0.001		<0.001		<0.001
MSM	97.5 ± 14.6		13.8 ± 2.8		14.3 ± 2.7		13.9 ± 2.4	
Heterosexual	96.8 ± 13.6		14.6 ± 2.8		14.1 ± 2.5		13.8 ± 2.5	
PWID	84.5 ± 15.7		12.7 ± 3.4		12.5 ± 2.6		12.3 ± 2.1	
Others	99.1 ± 11.9		13.9 ± 3.1		14.9 ± 2.1		14.2 ± 1.9	
Current HAART Treatment		<0.001		<0.001		<0.001		<0.001
Yes	96.4 ± 14.4		14.1 ± 3.0		14.2 ± 2.7		13.9 ± 2.3	
No	87.2 ± 16.5		12.7 ± 3.0		12.9 ± 2.6		12.4 ± 2.2	
Opportunistic Infection		<0.001		<0.001		<0.001		<0.001
Yes	88.5 ± 16.8		12.9 ± 3.3		13.1 ± 2.9		12.9 ± 2.5	
No	97.5 ± 13.5		14.3 ± 2.8		14.3 ± 2.5		13.9 ± 2.2	

*MSM (men-sex-men), PWID (people who inject drug), HAART (highly active antiretroviral treatment). Total respondents = 305

Table 4-7: Distribution of sociodemographic characteristics and HIV-related variables with social relationship, environment, spirituality and overall QOL mean score domain

Variables	Social relationship Mean ± SD	p-value	Environment Mean ± SD	p-value	SRPB Mean ± SD	p-value	Overall QOL Mean ± SD	p-value
Gender		0.765		0.878		0.494		0.242
Male	12.9 ± 3.2		13.5 ± 2.9		12.3 ± 2.4		13.8 ± 3.1	
Female	12.8 ± 3.3		13.6 ± 2.4		12.7 ± 2.1		14.6 ± 3.2	
Ethnicity		0.558		0.946		<0.001		0.590
Malay	12.8 ± 3.2		13.6 ± 3.0		12.1 ± 2.4		13.7 ± 3.4	
Chinese	13.3 ± 2.6		13.4 ± 2.4		13.4 ± 1.9		13.9 ± 2.4	
Indian/others	12.9 ± 3.9		13.6 ± 2.5		12.1 ± 2.5		14.3 ± 2.7	
Education Level		<0.001		<0.001		0.082		0.002
No tertiary	13.9 ± 3.2		14.9 ± 2.3		12.6 ± 2.3		14.5 ± 2.7	
Tertiary	12.4 ± 3.1		12.6 ± 2.7		12.2 ± 2.4		13.4 ±3.3	
Marital Status		0.002		0.031		0.291		0.009
Unmarried	12.7 ± 3.1		13.4 ± 2.8		12.3 ± 2.4		13.6 ± 3.1	
Married	14.1 ± 3.2		14.2 ± 2.6		12.7 ± 2.4		14.8 ± 3.1	
Employment Status		<0.001		<0.001		0.006		<0.001
Employed	13.6 ± 2.8		14.3 ± 2.3		12.6 ± 2.2		14.6 ± 2.7	
Unemployed	11.5 ± 3.4		11.8 ± 2.9		11.8 ± 2.6		12.3 ± 3.5	
Mode of Transmission		<0.001		<0.001		0.009		<0.001
MSM	13.7 ± 2.8		14.7 ± 2.4		12.7 ± 2.4		14.4 ± 2.7	
Heterosexual	13.3 ± 3.1		14.0 ± 2.3		12.5 ± 2.1		14.5 ± 2.8	
Injecting drug user	11.3 ± 3.2		11.5 ± 2.9		11.7 ± 2.3		12.4 ± 3.5	
Others	14.4 ± 3.0		13.9 ± 1.9		12.9 ± 2.4		14.6 ± 2.7	
Current HAART Treatment		0.018		<0.001		0.024		<0.001
Yes	13.2 ± 3.1		13.9 ± 2.5		12.6 ± 2.3		14.4 ± 2.7	
No	12.3 ± 3.3		12.5 ± 3.2		11.9 ± 2.3		12.6 ± 3.6	
Opportunistic Infection		<0.001		<0.001		0.003		<0.001
Yes	12.1 ± 3.3		12.5 ± 3.0		11.9 ± 2.4		13.1 ± 3.4	
No	13.6 ± 2.9		14.3 ± 2.3		12.7 ± 2.2		14.4 ± 2.8	

*MSM (men-sex-men), PWID (people who inject drug), HAART (highly active antiretroviral treatment). ** SRPB = Spirituality/ Religion/ Personal Belief. Total participants = 305

4.6 Stigma Among PLHIV

The perceived stigma survey involved 200 respondents from Tanglin HIV Clinic (n = 168) and CBOs (n = 32). There were 91.5% (n = 183) men and 8.5% (n = 17) women. Due to a technical flaw, the UMMC respondents (n = 105) were not included in this analysis as the stigma component was added after data collection had commenced in UMMC. As data collection was conducted consecutively from one centre to the other, it was impossible to repeat the data collection in UMMC.

4.6.1 Total HIV Stigma Score

The subject's perceived stigma was assessed using the HIV stigma scale. Possible scores ranged from 40 to 160, and higher scores indicate a higher degree of perceived stigma. Table 4.8 describes the proportion of respondents who endorsed each of the perceived stigma domains. On average, more than 99% of respondents endorsed all stigma items asked.

The overall stigma score for this study was moderate, with a mean total score of 100.4 ± 17.3. The score of the HIV Stigma Scale (HSS-21) was positively correlated with the score of depression and negatively correlated with the score of QOL. The total stigma scores ranged from 49 to 153 (mean score 100.4 ± 17.3), personalised stigma subscales ranged from 18 to 72 (mean score 44.4 ± 9.06); disclosure stigma subscales scores ranged from 15 to 38 (mean score 26.9 ± 4.5); negative self-image scores ranged from 16 to 51 (mean score 30.7 ± 6.5), and perceived public attitude subscale score ranged from 20 to 80 (mean score 50.8 ± 9.6). The highest stigma was recorded in the disclosure concerns, and the least affected was the negative self-image and personalised stigma.

a) Personalised Stigma

Approximately three-fourths (71%, n = 142) reported that most PLHIV were rejected when others know about their HIV serostatus. More than half (61.3%, n = 122) reported that they had been hurt by how people reacted towards them when they knew of their HIV serostatus, and 59.5% (n = 119) reported that some people act as though it is their fault that they contracted HIV.

b) Disclosure Concerns

Disclosure concerns subscales showed 79.4% (n = 158) were very careful concerning whom they informed about their HIV status and 70.4% (n = 140) reported that in many areas in their life, no one knew their HIV status and 66.8% (n = 133) claimed they work hard to keep their HIV status secret.

c) Negative Self-image

42.5% (n = 85) of respondents reported people's attitude towards HIV makes them feel worse about themselves and 43.5% (n = 87) felt that they are not as good as other people because they were HIV positive.

d) Perceived Public Attitude

Some 62.4% (n = 123) of respondents indicated that it is risky to tell someone they have HIV, while 63.5% (n = 127) indicated that they would lose their jobs if their employers knew their HIV status and 59.5% (n = 119) reported that some people blamed them for having HIV.

Table 4-8 : Proportion of respondents who endorsed the perceived stigma items on the Berger Stigma Scale and items reflected in each domain

Stigma Domain [c]	Perceived Stigma Items	Mean ± (SD)	Agree and strongly agree n (%)
DC	In many areas of my life, no one knows that I have HIV	2.9 ± 0.8	140 (70.4%)
NSI	I feel guilty because I have HIV	2.4 ± 0.9	92 (46.0%)
NSI	People's attitudes about HIV make me feel worse about myself	2.4 ± 0.8	85 (42.5%)
DC, PC	Telling someone I have HIV is risky	2.7 ± 0.8	123 (62.4%)
PC	People with HIV lose their jobs when their employers find out	2.7 ± 0.9	127 (63.5%)
DC, NSI	I work hard to keep my HIV a secret	2.8 ± 0.8	133 (66.8%)
NSI	I feel I am not as good a person as others because I have HIV	2.3 ± 0.8	87 (43.5%)
NSI	I never feel ashamed of having HIV	2.6 ± 0.7	111 (55.5%)
PC	People with HIV are treated like outcasts	2.6 ± 0.8	114 (57.0%)
PC	Most people believe that a person who has HIV is dirty	2.6 ± 0.7	124 (62.0%)
DC, NSI, PC	It is easier to avoid new friendships than worry about telling someone that I have HIV	2.5 ± 0.7	99 (49.5%)
PS, NSI, PC	Having HIV makes me feel unclean	2.1 ± 0.8	59 (29.5%)
NSI	Since learning I have HIV, I feel set apart and isolated from the rest of the world	2.2 ± 0.8	68 (34.0%)
PC	Most people think that a person with HIV is disgusting	2.5 ± 0.8	108 (54.0%)
NSI	Having HIV makes me feel that I'm a bad person	2.1 ± 0.8	53 (26.6%)
PS, PC	Most people with HIV are rejected when others find out	2.7 ± 0.7	142 (71.0%)
DC	I am very careful who I tell that I have HIV	2.9 ± 0.7	158 (79.4%)
PS	Some people who know I have HIV have grown more distant	2.4 ± 0.7	88 (44.0%)
DC, PC	Since learning I have HIV, I worry about people discriminating against me	2.6 ± 0.7	116 (58.0%)
PC	Most people are uncomfortable around someone with HIV	2.8 ± 0.7	146 (73.0%)
DC	I never feel the need to hide the fact that I have HIV	2.6 ± 0.8	104 (52.0%)
DC, PC	I worry that people may judge me when they learn I have HIV	2.5 ± 0.7	106 (53.0%)

Table 4.8: Proportion of respondents who endorsed the perceived stigma items on the Berger Stigma Scale and items reflected in each domain. (Continued)

Stigma Domain [c]	Perceived Stigma Items	Mean ± (SD)	Agree and strongly agree n (%)
NSI	Having HIV in my body is disgusting to me	2.1 ± 0.8	55 (27.5%)
DC	I worry that people who know I have HIV will tell others	2.7 ± 0.8	130 (65.0%)
PS, NSI, PC	I regret having told some people that I have HIV	2.6 ± 0.7	112 (56.0%)
PS, NSI, PC	As a rule, telling others that I have HIV has been a mistake	2.5 ± 0.7	102 (51.0%)
PS, PC	Some people avoid touching me once they know I have HIV	2.4 ± 0.7	88 (44.0%)
PS	People I care about stopped calling after learning I have HIV	2.3 ± 0.8	74 (37.2%)
PS, PC	People have told me that getting HIV is what I deserve for how I lived my life	2.4 ± 0.7	99 (49.5%)
PS	Some people close to me are afraid others will reject them if it becomes known that I have HIV	2.5 ± 0.7	102 (51.0%)
PS, PC	People don't want me around their children once they know I have HIV	2.4 ± 0.7	96 (48.0%)
PS, PC	People have physically backed away from me when they learn I have HIV	2.5 ± 0.7	102 (51.0%)
PS, PC	Some people act as though it's my fault I have HIV	2.6 ± 0.7	119 (59.5%)
PS	I have stopped socialising with some people because of their reactions to my having HIV	2.5 ± 0.7	104 (52.2%)
PS	I have lost friends by telling them I have HIV	2.4 ± 0.7	87 (43.5%)
DC	I have told people close to me to keep the fact that I have HIV a secret	2.7 ± 0.7	126 (63.0%)
PS, NSI, PC	People who know I have HIV tend to ignore my good points	2.4 ± 0.7	80 (40.0%)
PS, NSI, PC	People seem afraid of me once they learn I have HIV	2.5 ± 0.7	103 (51.5%)
PS, PC	When people learn you have HIV, they look for flaws in your character	2.5 ± 0.7	106 (53.0%)

Total respondents = 200 PS=Personalised Stigma; DC=Disclosure Concerns; PC=Public Concerns; NSI= Negative Self-Image

Table 4.9 summarises the distribution of HIV stigma scores. Total mean and median stigma scores were similar, 100.4 ± 17.3 and 101, respectively. The highest stigma was in the disclosure domain (mean 2.7 ± 0.4) and lowest in the negative self-image domain (2.4 ± 0.5). The scores for the subscale personalised stigma ranged from 18 to 72, with a mean score of 44.4 ± 9.1. The disclosure concerns subscale ranged from 15 to 38, with a mean score of 26.9 ± 4.5. The scores for the negative self-image subscale ranged from 16 to 51 with a mean score of 30.7 ± 6.5 and the scores for public attitude subscale ranged from 20 to 80 with a mean score of 50.8 ± 9.6.

Table 4-9: Distribution of stigma score

Stigma Domains	Mean score of all items in domain Mean ± SD	Median	Mean score for each item in domain Mean ± SD	Min-Max
Total Stigma Score	**100.4 ± 17.3**	**101.0**	**-**	**49-153**
Personalised Stigma	44.4 ± 9.1	44.3	2.5 ± 0.5	18-72
Disclosure Concerns	26.9 ± 4.5	27.0	2.7 ± 0.4	15-38
Negative Self-Image	30.7 ± 6.5	30.0	2.4 ± 0.5	16-51
Perceived Public Attitude	50.8 ± 9.6	50.5	2.5 ± 0.5	20-80

Total respondents =200

Table 4.10 and 4.11 presents the mean scores of total stigma and its domain by sociodemographic characteristics and HIV-related variables. There were no significant associations between gender, ethnicity, marital status, employment status, current HAART and opportunistic infection with total stigma score. Respondents with non-tertiary education reported a higher mean total stigma score (mean score 102.1 ± 16.6) compared to those with tertiary education (mean score 96.3 ± 18.5), p<0.001. A higher total stigma score was reported among PWID and MSM with (mean score 101.5 ± 14.6) and (mean score 100.3 ± 16.7) with (p<0.001).

Personalised stigma was significantly higher among those without tertiary education (mean score 45.7 ± 8.5) and having opportunistic infections (mean score 46.0 ± 8.6). Disclosure concerns were higher among MSM (mean score 28.9 ± 4.4) followed by others (mean score 27.2 ± 4.6), p<0.001. Negative self-image was significantly higher among those with non-tertiary education level (mean score 31.7 ± 6.1) p<0.001. Perceived public domain was highest among PWID with (mean score of 52.0 ± 7.9); p<0.001. Those with primary and secondary education level was significantly associated with personalised stigma, negative self-image and perceived public stigma with a mean score of 45.7 ± 8.5, 31.7 ± 6.1 and 51.9 ± 4.1, respectively. Those having an opportunistic infection had a significant association with personalised stigma (mean score 46.0 ± 8.6); p=0.015.

Table 4-10: Distribution of sociodemographic characteristics and HIV-related variables with total stigma, personalised and disclosure domain score

Variables	Total Stigma score Mean ± SD	p-value	Personalised domain score Mean ± SD	p-value	Disclosure domain score Mean ± SD	p-value
Gender		0.79		0.44		0.64
Male	100.3 ± 16.9		44.3 ± 8.9		26.9 ± 4.3	
Female	101.5 ± 22.1		46.1 ± 10.3		26.4 ± 5.6	
Ethnicity		0.63		0.39		0.48
Malay	100.6 ± 17.4		44.6 ± 9.1		27.0 ± 4.5	
Chinese	97.9 ± 14.2		42.8 ± 7.1		25.9 ± 4.0	
Indian/others	102.6 ± 20.99		46.4 ± 11.1		27.3 ± 4.9	
Education Level		0.03		0.004		0.16
Non-tertiary	102.1 ± 16.6		45.7 ± 8.5		26.6 ± 4.2	
Tertiary	96.3 ± 18.5		41.7 ± 9.8		27.7 ± 5.1	
Marital Status		0.37		0.38		0.31
Unmarried	100.9 ± 16.5		44.8 ± 3.8		27.1 ± 4.2	
Married	97.9 ± 20.9		43.3 ± 9.8		26.2 ± 5.4	
Employment Status		0.20		0.07		0.46
Unemployed	102.2 ± 16.0		45.9 ± 8.2		26.6 ± 4.3	
Employed	99.1 ± 18.1		43.5 ± 9.5		27.1 ± 4.6	
Mode of Transmission		<0.001		0.10		<0.001
MSM	100.3 ± 16.7		42.9 ± 8.9		28.9 ± 4.4	
Heterosexual	99.8 ± 22.1		44.3 ± 11.2		26.7 ± 4.9	
PWID	101.5 ± 14.6		46.2 ± 7.5		25.7 ± 3.7	
Others	95.9 ± 19.4		41.8 ± 9.9		27.2 ± 4.6	
Current HAART Treatment		0.78		0.88		0.52
Yes	100.1 ± 17.5		44.4 ± 9.3		27.1 ± 4.4	
No	100.8 ± 17.2		44.6 ± 8.8		26.6 ± 4.5	
Opportunistic Infection		0.23		0.015		0.05
Yes	101.8 ± 16.7		46.0 ± 8.6		26.3 ± 2.4	
No	98.9 ± 17.9		42.9 ± 9.3		27.5 ± 4.6	

*MSM (men-sex-men), PWID (people who inject drug), HAART (highly active antiretroviral treatment). Total respondents =200

Table 4-11: Distribution of sociodemographic characteristics and HIV-related variables with negative self-image and perceived public domain score

Variables	Negative self-image domain score Mean ± SD	p-value	Perceived public domain Mean ± SD	p-value
Gender		0.92		0.80
Male	30.7 ± 6.3		50.7 ± 9.5	
Female	30.9 ± 9.2		51.4 ± 11.8	
Ethnicity		0.92		0.61
Malay	30.7 ± 6.7		50.9 ± 9.6	
Chinese	30.6 ± 5.7		49.3 ± 7.8	
Indian/others	31.3 ± 6.8		51.9 ± 12.4	
Education Level		0.001		0.006
Non-tertiary	31.7 ± 6.1		51.9 ± 4.1	
Tertiary	28.4 ± 7.0		47.9 ± 10.4	
Marital Status		0.80		0.32
Unmarried	30.8 ± 6.2		51.1 ± 9.2	
Married	30.5 ± 8.2		49.3 ± 11.6	
Employment Status		0.18		0.16
Unemployed	31.5 ± 6.4		51.9 ±8.8	
Employed	30.2 ± 6.6		49.9 ± 10.1	
Mode of Transmission		0.55		0.009
MSM	29.9 ± 6.2		50.3 ± 9.2	
Heterosexual	31.3 ± 8.5		50.0 ± 12.4	
PWID	31.2 ± 5.5		52.0 ± 7.9	
Others	29.6 ± 7.0		47.9 ± 11.1	
Current HAART Treatment		0.55		0.79
Yes	30.5 ± 6.7		50.6 ± 9.9	
No	31.1 ± 6.2		51.0 ± 9.3	
Opportunistic Infection		0.12		0.14
Yes	31.4 ± 6.2		51.8 ± 9.1	
No	30.0 ± 6.9		49.8 ± 10.1	

*MSM (men-sex-men), PWID (people who inject drug), HAART (highly active antiretroviral treatment). Total respondents =200

4.7 Stigma and Quality of Life (QOL) Among PLHIV

This part of the analysis answers the fourth research objective. The total stigma score was inversely associated with total QOL (r = -0.362, p<0.001) indicating that as the perception of stigma increases, quality of life decreases. Personalised stigma, negative self-image, public attitude and total stigma were significantly correlated with total QOL and all domains (p< 0.01). Table 4.12 shows the correlation matrix between QOL domains and stigma domains.

Table 4-12: Correlation matrix between stigma domains with quality of life

Stigma domain	**QOL DOMAIN**							
	Total QOL	**Physical Domain**	**Psychological Domain**	**Level of independence Domain**	**Social Relationship Domain**	**Environment Domain**	***SRPB**	**Overall QOL**
Personalised Stigma								
r	-0.39	-0.29	-0.41	-0.31	-0.46	-0.38	-0.18	-0.18
(p-value)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(0.011)	(0.013)
Disclosure Concerns								
r	-0.08	-0.15	-0.06	-0.07	-0.01	0.03	-0.14	0.019
(p-value)	(0.247)	(0.038)	(0.42)	(0.304)	(0.145)	(0.650)	(0.046)	(0.785)
Negative Self-Image								
r	-0.40	-0.35	-0.39	-0.28	-0.42	-0.31	-0.25	-0.22
(p-value)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(0.002)
Public Attitude								
r	-0.34	-0.26	-0.34	-0.27	-0.38	-0.32	-0.17	-0.15
(p-value)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(0.015)	(0.034)
Total Stigma								
r	-0.36	-0.30	0.36	-0.28	-0.39	-0.29	-0.220	-0.16
(p-value)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(0.002)	(0.022)

Total respondents =200

* SRPB = Spirituality / Religion / Personal Belief Domain

Referring to Tables 4.13 and 4.14 in the crude and adjusted regression model, total QOL and all quality of life domains had significant negative association with all stigma domains. Disclosure stigma was significantly associated with total QOL, level of social relationship and environment domain after being adjusted for age, CD4 level, gender, ethnicity, marital status, education level, employment status, income, mode of transmission, co-infection, HAART therapy and survey centre (crude = - 0.29 p = 0.247, adjusted β = - 0.70, p= 0.001) (crude β = - 0.08 p = 0.145, adjusted β = - 0.17, p = 0.001) and (crude β = - 0.02 p = 0.650, adjusted β = - 0.09, p = 0.023).

Table 4-13 : Association between stigma domain with total quality of life, physical, psychological and level of independence domain

Stigma Score	Total Quality of Life		Physical Domain		Psychological Domain		Level of Independence Domain	
	β (95%CI)	p-value	β (95%CI)	p-value	β (95%CI)	p-value	β (95%CI)	p-value
Total Stigma								
Crude	-0.33 (-0.45, -0.21)	<0.001	-0.1 (-0.2, 0.0)	<0.001	-0.06 (-0.08, -0.03)	<0.001	-0.04 (-0.06, -0.02)	<0.001
Adjusted	-0.28 (-0.38, -0.18)	<0.001	-0.05 (-0.07, -0.03)	<0.001	-0.05 (-0.07, -0.03)	<0.001	-0.03 (-0.05, -0.02)	<0.001
Personalised								
Crude	-0.69 (-0.92, -0.47)	<0.001	-0.10 (-0.15, -0.06)	<0.001	-0.12 (-0.16, -0.08)	<0.001	-0.08 (-0.11, -0.05)	<0.001
Adjusted	-0.57 (-0.76, -0.38)	<0.001	-0.09 (-0.14, -0.05)	<0.001	-0.10 (-0.14, -0.07)	<0.001	-0.06 (-0.09, -0.03)	<0.001
Disclosure								
Crude	-0.29 (-0.79, 0.21)	0.247	-0.11 (-0.21, -0.01)	0.038	-0.03 (-0.12, 0.05)	0.417	-0.04 (-0.11, 0.04)	0.304
Adjusted	-0.70 (-1.1, -0.28)	0.001	-0.13 (-0.21, -0.01)	0.007	-0.07 (-0.17, -0.02)	0.417	-0.09 (-0.16, 0.03)	0.304
Negative- Self-Image								
Crude	-0.98 (-1.29, -0.66)	<0.001	-0.17 (-0.24, -0.11)	<0.001	-0.16 (-0.21, -0.11)	<0.001	-0.10 (-0.15, -0.05)	<0.001
Adjusted	-0.81 (-1.08, -0.55)	<0.001	-0.15 (-0.21, -0.09)	<0.001	-0.14 (-0.18, -0.09)	<0.001	-0.08 (-0.12, -0.04)	<0.001
Public Attitude								
Crude	-0.57 (-0.78, -0.35)	<0.001	-0.09 (-0.13, -0.04)	<0.001	-0.09 (-0.13, -0.06)	<0.001	-0.10 (-0.09, -0.03)	<0.001
Adjusted	-0.46 (-0.64, -0.28)	<0.001	-0.08 (-0.13, -0.04)	<0.001	-0.08 (-0.11, -0.05)	<0.001	-0.05 (-0.08, -0.02)	<0.001

*Adjusted for age, CD4 level, gender, ethnicity, marital status, education level, employment status, income, mode of transmission, co-infection, HAART therapy and survey centre. Total respondents =200

Table 4-14 : Association between stigma domain with the level of social relationship, environment and spirituality domain

Stigma Score	Level of Social Relationship Domain		Environment Domain		Spirituality/ Religion/ Personal Belief Domain	
	ß (95%CI)	**p-value**	**ß (95%CI)**	**p-value**	**ß (95%CI)**	**p-value**
Total Stigma						
Crude	-0.07 (-0.10, -0.05)	<0.001	-0.05 (-0.07, -0.03)	<0.001	-0.03 (-0.05, -0.01)	0.002
Adjusted	-0.07 (-0.09, -0.04)	<0.001	-0.04 (-0.06, -0.02)	<0.001	-0.02 (-0.04, -0.01)	0.012
Personalised						
Crude	-0.17 (-0.21, -0.12)	<0.001	-0.12 (-0.16, -0.08)	<0.001	-0.05 (-0.08, -0.01)	0.011
Adjusted	-0.14 (-0.18, -0.10)	<0.001	-0.09 (-0.12, -0.06)	<0.001	-0.04 (-0.07, -0.01)	0.037
Disclosure						
Crude	-0.08 (-0.18, 0.03)	0.145	0.02 (-0.07, 0.11)	0.650	-0.08 (-0.15, -0.00)	0.046
Adjusted	-0.17 (-0.26, -0.07)	0.001	-0.09 (-0.07, -0.11)	0.023	-0.07 (-0.15, 0.001)	0.069
Negative- Self-Image						
Crude	-0.21 (-0.27, -0.14)	<0.001	-0.14 (-0.20, -0.08)	<0.001	-0.09 (-0.14, -0.04)	<0.001
Adjusted	-0.18 (-0.24, -0.12)	<0.001	-0.11 (-0.15, -0.06)	<0.001	-0.07 (-0.12, -0.02)	0.005
Public Attitude						
Crude	-0.13 (-0.17, -0.08)	<0.001	-0.10 (-0.14, -0.06)	<0.001	-0.04 (-0.08, -0.01)	0.015
Adjusted	-0.11 (-0.15, -0.07)	<0.001	-0.07 (-0.11, -0.04)	<0.001	0.03 (-0.07, 0.00)	0.050

***Adjusted for age, CD4 level, gender, ethnicity, marital status, education level, employment status, income, mode of transmission,** co-infection, HAART therapy and survey centre.
Total respondents =200

4.8 Psychological Distress Among PLHIV

4.8.1 Depression, Anxiety and Stress Score (DASS)

Psychological distress consists of three major components, namely depression, anxiety and stress. Table 4.15 presents data pertaining to the prevalence and mean score for DASS. The depression scale showed that the majority (51.5%, n = 157) of respondents had a normal score while 17.2% (n = 52) were having mild depression, and 31.5% (n = 96) had moderate to extremely severe depression. The mean depression score was 4.9 ± 4.2.

For anxiety scale, the majority (41.6%, n = 127) of respondents were having a normal score. However, 39.7% (n = 121) respondents were having moderate to severe anxiety, followed by 18.7% (n = 57) who had mild anxiety. The mean anxiety score was 4.9 ± 3.7.

The stress scale showed most respondents had normal stress scores (69.5%, n =212), while 15.7% (n = 48) were having mild stress and 14.8% (n = 45) had moderate to severe stress. The mean stress score was 5.6 ± 4.1.

Table 4-15: Prevalence and mean score for Depression, Anxiety and Stress Scale (DASS-21)

Variables	n (%)	Mean ± SD	Median	Min-Max
Depression Score		4.9 ± 4.2	4.0	0 –20
Normal	157 (51.5%)			
Mild	52 (17.2%)			
Moderate to extremely severe	96 (31.5%)			
Anxiety Score		4.9 ± 3.7	4.0	0 - 21
Normal	127 (41.6%)			
Mild	57 (18.7%)			
Moderate to extremely severe	121 (39.7%)			
Stress Score		5.6 ± 4.1	6.0	0 – 20
Normal	212 (69.5%)			
Mild	48 (15.7%)			
Moderate to extremely severe	45 (14.8%)			

Total respondents =305

Data in Table 4.16 documents the mean score of DASS by sociodemographic characteristics and HIV-related variables. There were no significant associations between gender, ethnicity, education, marital status, current HAART, opportunistic infection and mode of transmission with depression score. Unemployed respondents had a higher mean depression score (mean score 5.8 ± 4.5), compared to employed respondents (mean score 4.6 ± 4.2), p = 0.02.

The anxiety scale showed no significant association between gender, ethnicity, education, current HAART and opportunistic infection with anxiety score. Unmarried respondents have a higher mean anxiety score (mean score 5.1 ± 3.8) compared to married respondents (mean score 3.8 ± 4.0) p = 0.025 and those with MSM risk of transmission were having a higher anxiety score (mean score 5.5 ± 4.6) compared to PWID (mean score 5.2 ± 3.7) and heterosexuals (mean score 3.8 ± 3.7) with p = 0.01.

A high mean stress score was seen among respondents with tertiary education level (mean score 6.4 ± 4.3, p = 0.01), those not on HAART therapy (mean score 6.4 ± 4.0, p = 0.04) and those having men-sex-men as a mode of transmission (mean score 6.6 ± 4.5, p = 0.009). People who inject drugs (PWID) also recorded a significantly high mean score (5.6 ± 4.0) followed by heterosexual transmission (mean score 4.7 ± 4.2, p = 0.009).

Table 4-16: Distribution of DASS by sociodemographic characteristics and HIV-related variables

Variables	Depression		Anxiety		**Stress**	
	Mean ± SD	**p-value**	**Mean ± SD**	**p-value**	**Mean ± SD**	**p-value**
Gender		0.36		0.34		0.91
Male	5.0 ± 4.4		4.9 ± 3.8		5.7 ± 4.3	
Female	4.2 ± 3.9		4.2 ± 3.6		5.6 ± 3.6	
Ethnicity		0.60		0.58		0.42
Malay	5.0 ± 4.0		5.0 ± 3.4		5.8 ± 3.7	
Chinese	4.6± 4.8		4.5 ± 4.8		5.1 ± 5.0	
Indian/others	5.5 ± 5.1		4.6 ± 4.0		6.1 ± 5.1	
Education Level		0.39		0.12		0.01
Non-tertiary	4.8 ± 4.4		4.6 ± 3.8		5.2 ± 4.1	
Tertiary	5.2 ± 4.3		5.3 ± 3.9		6.4 ± 4.3	
Marital Status		0.25		0.02		0.34
Unmarried	5.1 ± 4.3		5.1 ± 3.8		5.8 ± 4.3	
Married	4.4 ± 4.5		3.9 ± 4.0		5.2 ± 4.1	
Employment Status		0.02		0.09		0.09
Unemployed	5.8 ± 4.5		5.4 ± 3.8		6.2 ± 4.1	
Employed	4.6 ± 4.2		4.6 ± 3.8		5.4 ± 4.2	
Mode of Transmission		0.04		0.01		0.01
MSM	5.5 ± 4.6		5.5 ± 4.1		6.6 ± 4.5	
Heterosexual	3.9 ± 4.2		3.8 ± 3.7		4.7 ± 4.2	
PWID	5.4 ± 4.3		5.2 ± 3.7		5.6 ± 4.0	
Others	4.0 ± 2.8		4.2 ± 2.4		4.6 ± 2.8	
Current HAART Treatment		0.07		0.02		0.04
No	5.7 ± 4.3		5.7 ± 3.5		6.4 ± 4.0	
Yes	4.7 ± 4.3		4.5 ± 3.9		5.3 ± 4.3	
Opportunistic infection		0.15		0.09		0.46
Yes	5.4 ± 4.5		5.3 ± 3.7		5.9 ± 4.2	
No	4.7 ± 4.2		4.5 ± 3.9		5.5 ± 4.3	

*MSM (men-sex-men), PWID (people who inject drug), HAART (highly active antiretroviral treatment). Total respondents =305

4.9 Psychological Distress and Quality of Life (QOL) Among PLHIV

This part of the analysis answers the fifth research objective. Total QOL had a significant negative correlation to depression (r = -0.59, p<0.001), anxiety (r = -0.48, p<0.001) and stress (r = -0.44, p<0.001). All quality of life domains was negatively correlated with DASS p<0.001 (Table 4.17).

Table 4-17: Correlation between DASS with total quality of life and its domains

DASScore	QOL DOMAIN							
	Total QOL	Physical Domain	Psychological Domain	Level of independence Domain	Social Relationship Domain	Environment Domain	*SRPB Domain	Global QOL
Depression								
r	-0.54	- 0.53	-0.55	-0.37	-0.40	-0.36	-0.39	-0.39
(p-value)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)
Anxiety								
r	-0.48	-0.53	-0.46	-0.35	-0.31	-0.33	-0.30	-0.36
(p-value)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)
Stress								
r	-0.44	-0.48	-0.45	-0.31	-0.30	-0.29	-0.31	-0.29
(p-value)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)	(<0.001)

Total respondents =305

*SRPB = Spirituality / Religion / Personal Belief Domain

Referring to Table 4.18 in the crude and adjusted regression models, depression (crude β = - 1.95 p<0.001, adjusted β = - 1.56, p=0.001), anxiety (crude β = - 1.96 p<0.001, adjusted β = - 1.53, p=0.001) and stress (crude β = - 1.63 p<0.001, adjusted β = - 1.35, p<0.001) had significant negative association with total QOL score. Depression, anxiety and stress had significant negative association with all QOL domain scores, p <0.001.

Table 4-18 : The association between DASS with quality of life domain

	Total Quality of Life Score ß (95%CI)	Physical Domain ß (95%CI)	Psychological Domain ß (95%CI)	Level of Independence Domain ß (95%CI)	Level of Social Relationship Domain ß (95%CI)	Environment Domain ß (95%CI)	****SRPB Domain ß(95%CI)
Depression Scale							
Crude	-1.95* (-2.3, -1.6)	-0.38* (-0.45, -0.31)	-0.35* (-0.40, -0.29)	-0.20* (-0.26, -0.14)	-0.29* (-0.38, -0.22)	-0.24* (-0.30, -0.17)	-0.21* (-0.27, -0.16)
Adjusted	-1.56* (-1.9, -1.2)	-0.32* (-0.41, -0.24)	-0.27* (-0.33, -0.19)	-0.16* (-0.22, -0.09)	-0.26* (-0.35, -0.17)	-0.19* (-0.26, -0.13)	-0.16* (-0.23, -0.09)
Anxiety Scale							
Crude	-1.96* (-2.4, -1.6)	-0.43* (-0.51, -0.35)	-0.32* (-0.39, -0.25)	-0.22* (-0.28, -0.15)	-0.26* (-0.35, -0.17)	-0.24* (-0.32, -0.17)	-0.18* (-0.25, -0.12)
Adjusted	-1.53* (-1.9, -1.0)	-0.36* (-0.46, -0.27)	-0.23* (-0.31, -0.15)	-0.18* (-0.25, -0.10)	-0.19* (-0.31, -0.09)	-0.21* (-0.28, -0.13)	-0.13** (-0.20, -0.05)
Stress Scale							
Crude	-1.63* (-2.0, -1.3)	-0.35* (-0.42, -0.28)	-0.29* (-0.36, -0.23)	-0.18* (-0.24, -0.12)	-0.23* (-0.31, -0.15)	-0.19* (-0.26, -0.12)	-0.18* (-0.23, -0.12)
Adjusted	-1.35* (-1.78, -0.92)	-0.29* (-0.39, -0.19)	-0.23* (-0.31, -0.15)	-0.15* (-0.23, -0.08)	-0.20* (-0.30, -0.10)	-0.19* (-0.26, -0.11)	-0.12** (-0.19, -0.04)

* Significant at the 0.001 level (p <0.001) ** Significant at the 0.05 level (p <0.05)
Adjusted for treatment centres, age, gender, ethnicity, marital status, education level, employment status, income, mode of transmission, co-infection and HAART therapy. * SRPB = Spirituality/ Religion/ Personal Belief Domain. Total respondents = 305

Table 4.19 shows the QOL mean score by categories of DASS. Those categorised as not severe include those having normal and mild scores. Those categorised as severe were those having moderate to extremely severe scores. Respondents without severe DASS had a higher mean total QOL score (mean score 97.4 ± 13.6, mean score 97.9 ± 13.6, mean score 96.2 ± 14.4) respectively ($p < 0.001$). The mean scores for all QOL domains were significantly higher among those without severe DASS ($p < 0.001$). There were significantly lower mean total QOL scores for severe depression (mean score 80.9 ± 15.0) severe anxiety (mean score 84.8 ± 15.7) and severe stress (mean score 78.9 ± 13.6).

Table 4-19 : QOL domains mean score by DASS

DASScale	n	Total QOL Mean ± SD	Physical Domain Mean ± SD	Psychological Domain Mean ± SD	Level of Independence Domain Mean ± SD	Level of Social Relationship Domain Mean ± SD	Environment Domain Mean ± SD	SRPB* Mean ± SD
Depression Scale								
Not severe	209	97.4 ± 13.6**	14.4 ± 2.7**	14.5 ± 2.3**	13.8 ± 2.2**	13.5 ± 3.0**	13.9 ± 2.7**	12.7 ± 2.2**
Severe	96	80.9 ± 15.0**	11.3 ± 2.9**	11.4 ± 2.8**	12.1 ± 2.5**	10.9 ± 2.9**	12.1 ± 2.7**	11.0 ± 2.4**
Anxiety Scale								
Not severe	184	97.9 ± 13.6**	14.6 ± 2.8**	14.5 ± 2.3**	13.9 ± 2.1**	13.5 ± 3.1**	14.0 ± 2.6**	12.8 ± 2.3**
Severe	121	84.8 ± 15.7**	11.8 ± 2.8**	12.2 ± 2.8**	12.5 ± 2.6**	11.7 ± 3.1**	12.5 ± 2.9**	11.5 ± 2.3**
Stress Scale								
Not severe	260	96.2 ± 14.4**	14.2 ± 2.8**	14.3 ± 2.4**	13.8 ± 2.2**	13.3 ± 3.1**	13.8 ± 2.7**	12.6 ± 2.2**
Severe	45	78.9 ± 13.6**	10.8 ± 2.8**	10.9 ± 2.6**	11.5 ± 2.2**	10.9 ± 2.8**	11.8 ± 2.7**	10.8 ± 2.5**

* SRPB = Spirituality/ Religion/ Personal Belief Domain
** Significant at the 0.05 level ($p < 0.05$).
*** Not severe = normal and mild, Severe = moderate to extremely severe
Total respondents =305

Referring to Table 4.20, in the crude and adjusted logistic regression models, severe depression was associated with lower odds of good quality of life (crude OR = 0.92 p<0.001, adjusted OR = 0.92; p<0.001). In the crude and adjusted logistic regression models, when compared to those without severe anxiety, those with severe anxiety have lower odds of good quality of life (crude OR = 0.94; p<0.001, adjusted OR = 0.93; p<0.001). Those with severe stress were associated with lower odds of good quality of life (crude OR = 0.92; p<0.000, adjusted OR = 0.89; p<0.001).

Table 4-20 : Associations between DASS with quality of life

DASScale	**Odds of good quality of life**			
	Crude		**Adjusted**	
	OR (95% CI)	**p-value**	**OR (95% CI)**	**p-value**
Depression Scale				
Not severe	1.00 (reference)	<0.001	1.00 (reference)	<0.001
Severe	0.92 (0.89, 0.94)		0.92 (0.89, 0.95)	
Anxiety Scale				
Not severe	1.00 (reference)	<0.001	1.00 (reference)	<0.001
Severe	0.94 (0.92, 0.96)		0.93 (0.91, 0.96)	
Stress Scale				
Not severe	1.00 (reference)	<0.001	1.00 (reference)	<0.001
Severe	0.92 (0.90, 0.95)		0.89 (0.85, 0.94)	

*Adjusted for age, CD4 level, gender, ethnicity, marital status, education level, employment status, income, mode of transmission, co-infection, HAART therapy and survey centres
** Not severe = normal and mild, Severe = moderate to extremely severe
Total respondents =305

4.10 Stigma and Psychological Distress Among PLHIV

This part of the analysis answers the sixth research objective. The total stigma score was positively associated with depression (r = 0.40, p < 0.001) anxiety (r = 0.27, p < 0.001) and stress (r = 0.36, p < 0.001) indicating the perception of stigma increased in relation to increase in DASS. Personalised stigma, disclosure stigma, negative self-image and personal public attitude were significantly correlated with depression, anxiety and stress (p< 0.01). Table 4.21 shows a correlation matrix between stigma domain with the DAS Scale.

Table 4-21 : Correlation between total stigma score and its domain with DASS

Stigma Domain	DASS SCORE					
	Depression		Anxiety		Stress	
	r	p-value	r	p-value	r	p-value
Total Stigma	0.40	<0.001	0.27	<0.001	0.36	<0.001
Personalised stigma	0.35	<0.001	0.24	0.001	0.31	<0.001
Disclosure Domain	0.30	<0.001	0.17	0.019	0.29	<0.001
Negative self-image	0.41	<0.001	0.27	<0.001	0.34	<0.001
Personal Public Attitude	0.38	<0.001	0.26	<0.001	0.33	<0.001

Total respondents =200

Referring to Table 4.22, in the crude and adjusted regression model, total stigma had a significant positive association with depression, anxiety and stress, p<0.001. Personalised stigma, disclosure stigma, negative self-image and personal public attitude were significantly associated with DASS after being adjusted for age, CD4 level, gender, ethnicity, education level, marital status, mode of transmission, employment status, income, co-infection, HAART therapy and survey centres.

Table 4-22 : Association between total stigma and stigma domains with depression, anxiety and stress

Stigma Domain	Depression		Anxiety		Stress	
	Crude ß (95%CI)	Adjusted ß (95%CI)	Crude ß (95%CI)	Adjusted ß (95%CI)	Crude ß (95%CI)	Adjusted ß (95%CI)
Total Stigma Score	0.09* (0.07, 0.13)	0.09* (0.07, 0.12)	0.06* (0.03, 0.09)	0.06* (0.03, 0.009)	0.08* (0.05, 0.01)	0.08* (0.06, 0.11)
Personalised Stigma	0.16* (0.09, 0.22)	0.15* (0.09, 0.20)	0.09** (0.04, 0.15)	0.11* (0.05, 0.16)	0.14* (0.08, 0.19)	0.18* (0.11, 0.22)
Disclosure Concerns	0.28* (0.15, 0.39)	0.29* (0.18, 0.42)	0.14** (0.02, 0.25)	0.14** (0.26, 0.04)	0.26* (0.14, 0.38)	0.24* (0.13, 0.36)
Negative Self-Image	0.25* (0.17, 0.33)	0.26* (0.18, 0.34)	0.15* (0.08, 0.23)	0.16* (0.09, 0.23)	0.21* (0.13, 0.29)	0.22* (0.15, 0.29)
Personal Public Attitude	0.16* (0.10, 0.21)	0.17* (0.12, 0.22)	0.09* (0.05, 0.15)	0.11* (0.06, 0.16)	0.14* (0.08, 0.19)	0.15* (0.10, 0.19)

Total respondents =200 * Significant at the 0.001 level (p <0.001)

** Significant at the 0.05 level (p <0.05) * Adjusted for age, CD4 level, gender, ethnicity, marital status, education level, employment status, income, mode of transmission, co-infection, HAART therapy and survey centres

Referring to Table 4.23, in the crude and adjusted logistic regression models, higher level of stigma was associated with higher odds of depression (crude OR = 1.04 p<0.000, adjusted OR = 1.05; p<0.001) and anxiety (crude OR = 1.03 p<0.000, adjusted OR = 1.04; p<0.001). The stress scale was not significantly associated when adjusted for gender, ethnicity, education level, marital status, employment, income, mode of transmission, opportunistic infections and HAART treatment and survey centres (crude OR = 1.03 p = 0.03, adjusted OR = 1.03; p = 0.05). Personalised stigma, negative self, the personal public attitude was associated with higher odds of depression, p<0.05. Personalised stigma, disclosure concerns, negative self, personal public attitude were associated with higher odds of anxiety with p<0.05 and only disclosure concerns was associated with higher odds of stress with p<0.05.

Table 4-23 : Associations between stigma domain score with DASS

Stigma domain	Odds of severe depression				Odds of severe anxiety				Odds of severe stress			
	Crude		Adjusted		Crude		Adjusted		Crude		Adjusted	
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
Total stigma	1.04* (1.02, 1.06)	<0.001	1.05* (1.02, 1.07)	<0.001	1.03 (1.01, 1.05)	<0.001	1.04 (1.02, 1.06)	<0.001	1.03 (1.00, 1.05)	0.03	1.03 (1.00, 1.06)	0.05
Personalised Stigma	1.07* (1.02, 1.11)	0.002	1.08** (1.03,1.14)	0.01	1.05 (1.01, 1.09)	0.009	1.07 (1.03, 1.11)	0.02	1.04 (0.99, 1.09)	0.08	1.06 (0.99, 1.12)	0.07
Disclosure Concerns	1.10* (1.02, 1.19)	0.01	1.02 (0.92, 1.14)	0.70	1.07 (1.00, 1.15)	0.05	1.09 (1.01, 1.18)	0.03	1.06 (0.96, 1.16)	0.24	1.12 (1.02, 1.24)	0.02
Negative Self-Image	1.13* (1.07, 1.19)	<0.001	1.14* (1.07, 1.22)	<0.001	1.09 (1.04, 1.14)	0.001	1.11 (1.05, 1.18)	<0.001	1.07 (1.00, 1.13)	0.04	1.07 (0.99, 1.15)	0.08
Public Attitude	1.07** (1.03, 1.11)	0.01	1.08** (1.04, 1.13)	0.001	1.06 (1.02, 1.09)	0.01	1.06 (1.02, 1.09)	0.01	1.04 (0.99, 1.08)	0.09	1.04 (0.99, 1.08)	0.09

* Significant at the 0.001 level (p <0.001)

** Significant at the 0.05 level (p <0.05)

***Adjusted for: gender, ethnicity, education level, marital status, employment, income, mode of transmission, opportunistic infections and HAART treatment and survey centres.

Total respondents = 200

4.11 Chapter Summary

This chapter described the results of data collected from 305 PLHIV. The descriptive analysis revealed that the majority of PLHIV in this study were male, unmarried, mean age of 37 years with primary and secondary education and having sexually risky behaviour. The characteristics of the participants from the three centres were significantly different. PLHIV from UMMC a has better quality of life compared to Tanglin HIV Clinic and CBOs. There was a significantly higher mean score in all QOL domains for UMMC respondents.

Out of the six domains in the QOL scale, the PLHIV of the current study scored highest in psychological and physical domains. In the psychological domain, those with tertiary education, employed, on HAART treatment and no opportunistic infection had significantly higher scores. Employed, on HAART treatment and not having opportunistic infection respondents had higher physical domain scores.

Respondents scored lowest in the spirituality, religion, personal belief domain (SRPB) and the social relationship domain. Those without tertiary education, unmarried, unemployed, had an opportunistic infection and being PWID had poor social relationships. In spirituality, religion and personal belief domain, Malay respondents, those who were unemployed, injecting drugs and having opportunistic infection were having lower mean domain scores.

This study found there was a moderate level of stigma with the highest score in the disclosure domain, meaning PLHIV were very concerned in controlling information about their HIV status. The lowest stigma score was reported in the negative self-image domain, where feelings of isolation, shame and guilt was less in this study. There was a significantly higher stigma score among PWID and MSM, along with those with primary and secondary education ($p<0.001$). The relationship between stigma and QOL were also demonstrated in this study. Total stigma and all stigma domains were negatively associated with QOL, where the higher the stigma level, the lower the person rates their quality of life. Overall stigma is inversely related to overall QOL, which depict PLHIV experience better QOL when they perceived low levels of stigma.

In this chapter, the impacts of psychological distress namely depression, anxiety and stress on QOL have been demonstrated. It was found that depression, anxiety and stress were important predictors of quality of life among PLHIV. This study showed that unemployed respondents, MSM and PWID have higher depression scores. Those who were unmarried, having MSM and injecting drug risk behaviour (PWID) and not on HAART treatment have significantly higher anxiety scores, while those with tertiary education level, having MSM and injecting drug risk behaviour (PWID) and not on HAART were having higher stress scores. MSM and PWID have significantly higher DASS. This study also showed that initiating HAART treatment was a good predictor of psychological well being .

Finally, this chapter described the association between stigma and psychological distress. Stigma was positively associated with depression, anxiety and stress, indicating that as the perception of stigma increased, depression, anxiety and stress also increased. Personalised stigma, negative self, the personal public attitude was associated with higher odds of depression and anxiety, while disclosure concerns were associated with higher odds of anxiety and stress.

CHAPTER 5: DISCUSSION

5.1 Chapter Overview

This chapter presents a discussion of the study findings in relation to the research objectives. The results of previous studies are used to compare and support the findings of this study. This is followed by an examination of the strengths and limitations of this research and a discussion on its implications for public health. Finally, a general conclusion and recommendations for further research are presented.

5.2 Introduction

Many studies have examined QOL among PLHIV (Basavarajaiah et al., 2012; Martina et al., 2015; Osei-Yeboah et al., 2017; Singh et al., 2013; Wakawa et al., 2014). Local references are important to determine local QOL aspects as different parts of the world have different cultural and systems values. Several studies in Malaysia had examined QOL among PLHIV (Choi et al., 2010; Chua & Han, 2014; Fadzil & Zahiruddin Othman, 2016; Hasanah et al., 2011; Othman et al., 2015; Zaidi et al., 2012). However, very few studies investigated self-perceived stigma, psychological distress, and their influence on QOL. This study utilised the cross-sectional design. It involved 305 PLHIV who were recruited from three survey centres from Kuala Lumpur. This study aimed to address issues regarding the quality of life, perceived stigma and psychological distress (depression, anxiety and stress) among PLHIV in the Federal Territory of Kuala Lumpur.

5.3 Respondents Characteristics

The study population had more men (92%, n = 280) than women. This figure is slightly above the national HIV population, with approximately 89% of the PLHIV being men (HIV/STI Section Ministry of Health Malaysia, 2016). Slightly more than one-third of the HIV population in this study consists of men having sex with men (MSM) (36.4%) followed by 29% (n = 89) people who inject drugs (PWID), and 26% (n = 80) who practice heterosexual sex. The mean age was 37.9 ± 9.79, which falls within the national PLHIV average age group (20 to 39 years) (HIV/STI Section Ministry of Health Malaysia, 2016). This group of young reproductive people are more vulnerable to HIV infection due to their mobility, living environment, peer group pressure, exploitation (sexually exploited or trafficked) and possibly being abused (UNICEF Malaysia, 2008). Direct comparison of study characteristics with previous studies in Malaysia is difficult due to different assessments being used, different target population, mode of transmission and healthcare setting (Choi et al., 2010; Fadzil & Zahiruddin Othman, 2016; Hasanah et al., 2011; Othman et al., 2015).

5.4 Quality of Life and Factors Associated with QOL

The findings of the current study suggest that the total quality of life of respondents were found to be in the range of low to moderate. In comparison, the level of total QOL score and the mean score of all domains for this study was lower than that recorded by Abdul Bari & Aida (2017) which utilised the Malay version of the WHOQOL-HIV BREF conducted in the same setting. However, both the current study and Abdul Bari & Aida (2017) showed a similar trend where the physical domain and the psychological domain were least affected while the social and spirituality domain were the most affected. Respondents scored worse in the social relationship domains suggesting that participants may perceive that they have a poor personal relationship with others and did not receive adequate social support.

The findings in this study were similar to earlier studies in this region (Hasanah et al., 2011; Imam et al., 2011; Zaidi et al., 2012) where social relationships are the most affected domain of QOL. This current study also found that social relationships were inversely related to stigma and depression. High stigma limits social interactions with others, while depression would lead to isolation from others, which both result in the poor social relationship among PLHIV. Social support is mostly influenced by cultural or social norms that surround the PLHIV (Martina et al., 2015). In the Malaysian context, where culture is closely tied with religious belief, PLHIV are commonly labelled as sinful and may result in rejection by their family members and the community. Diminish social support from surrounding people could result in a reduction of QOL among PLHIV.

Spirituality/religion/personal belief domain is the second most affected domain in QOL. This domain assesses the feelings, personal beliefs, concern about future, death and meaning of life (Abdul Bari & Aida, 2017). Spirituality and religion are centrally important for PLHIV as PLHIV experience multiple challenges following the HIV diagnosis and also along the process of disease progression (Utley & Wachholtz, 2011). An example of religious and spiritual coping methods among PLHIV are prayer, spiritual transformation and belief in a higher power or presence of God (Pargament et al., 2004). Also, Pargament et al. (2004) described religion as a product of coping to life events, and it influences how individuals analysed the situations, participate in activities and develop their own goals. Therefore, spirituality uniquely plays an important role in the well being of PLHIV, and it can be used to predict the disease outcomes (Pargament et al., 2004). Zaidi et al. (2012) reported that spiritual counselling might help boost the individual's sense of a meaningful life even though they were fearful of their future and very worried about death. Respondents of the current study may be lacking in religious/spiritual coping where clinical interventions with PLHIV have largely neglected religiousness and spirituality as resources for treatment (Harris, Thoresen, McCullough, & Larson (2015). Therefore, it is important to integrate the religious and spiritual dimension in treatment given to PLHIV.

Physical domain was the least affected QOL domain in the current study, which suggests the PLHIV ability to perform routine daily activities was not affected by the illness (Abdul Bari & Aida, 2017; Hasanah et al., 2011). This may be contributed by the follow up at the HIV clinic and availability of HAART treatment, supported by the significantly higher QOL among UMMC and Tanglin Health Clinic respondents in the current study compared to CBOs respondents. The majority of UMMC and Tanglin Health Clinic respondents were on HAART (86.7% and 72.6% respectively) while only 6.3% of respondents from CBOs were on current HAART treatment. The implementation of government policy in giving free HAART treatment is necessary to improve the QOL of PLHIV as detailed by the National Strategic Plan (NSP) on HIV and AIDS 2011-2015 and the NSP for HIV 2010-2020.

When analysing the factors associated with quality of life, this study found education level, marital status, employment status and current HAART therapy being significant factors. A recent review showed that stigma, low level of socioeconomic status and being younger than 35 years had shown a negative association with QOL (Ghisvand et al., 2019). Degroote and colleagues reported employment, immunological status, depression, social support and adherence were associated with QOL among PLHIV (Degroote et al., 2014).

The current study showed a higher level of education was associated with significantly higher QOL in the psychological domain, level of independence, social relationship and environment domain. Several studies in Croatia, Georgia and China (Karkashadze et al., 2017; Kovacević et al., 2006; Liping, Peng, Haijiang, Lahong, & Fan, 2015) found those with a higher level of education reported significantly higher ratings within the level of independence and environment domain of QOL. Others had reported along similar lines where low education level was associated with poor QOL in the psychological and environment domain (Da Silva et al., 2013). PLHIV with higher education level cope better with HIV (Mutabazi-Mwesigire et al., 2015) probably reflective of better social status, good income and better access to support services.

Consistent with other studies (Blalock et al., 2002; Mutabazi-Mwesigire et al., 2015), this study showed employed significantly gives better QOL in all domains except spirituality. This is an expected finding as employment provides income, social support, role identity and meaning in life among PLHIV. Good income was also found to be associated with adherence to HAART (Carballo et al., 2004). Therefore, having an employment programme to elevate the economic status of PLHIV is an important tool to achieve a good quality of life.

Respondents who are married in this study were found to have significantly higher QOL in all QOL domains except the spirituality domain. Few studies supported the findings of married participants reported better QOL for the social relationship domain and higher total QOL scores than those who are unmarried and widowed (Kovacević et al., 2006; Yathiraj Arjun et al., 2017). The family institution may contribute to good social support, and culturally family member would help them to overcome difficulties.

This study found a positive association between ARV and QOL, consistent with other studies (Liping et al., 2015; Georgia Karkashadze et al., 2017; Ghana Osei-Yeboah et al., 2017) which reported a positive effect of ARV on QOL. Andrea Tramarin and colleagues (2004) highlighted the evidence on the positive outcome of HAART towards the quality of life is so strong compared to the associated toxicities of HAART (for example diarrhoea, anaemia, lipodystrophy, dizziness, vivid dream, pancreatitis).

5.5 The Association Between Stigma and Quality of Life

This study refers to perceived stigma as "being aware of negative societal attitudes, fear of discrimination and feelings of shame being infected with HIV" (Loutfy et al., 2012). It also refers to the past appraisal of experiences of prejudice, stereotypes and discrimination from others towards themselves after being positive for HIV (Yuh, Ellwanger, Potts, & Ssenyonga, 2014). According to Deacon (2006), stigma always results in blaming, shaming and loss of status for the stigmatised person, especially in the eyes of the stigmatizer. However, it does not always have to result in discrimination or negative effect on the stigmatised individual. The overall stigma score for this study was considered to be moderate. The mean total score reported in this study was 100.4 ± (17.3). These findings fall within the range of 99.1 to 122.7 as reported by three previous studies conducted in Malaysia (Abdul Bari & Aida, 2017; Choi et al., 2010; Fadzil & Zahiruddin Othman, 2016).

When analysed according to different domains, the present study found that stigma was highest in the disclosure domain (keeping HIV status secret). Again, this finding is consistent with other studies done in Malaysia where the most affected stigma was disclosure concerns (Abdul Bari & Aida, 2017; Choi et al., 2010; Fadzil & Zahiruddin Othman, 2016). A study from China (Z. Li & Sheng, 2014) examining 161 PLHIV using a similar questionnaire also reported disclosure as the most affected domain. Self-disclosure is defined as "interpersonal interaction where one person deliberately shares private information (including thoughts, feelings and experiences) of a personal nature with another person" (Derlega, Winstead, Greene, Serovich, & Elwood, 2004). PLHIV experienced multiple stressors related to decision to whom, when, what and how to disclose their serostatus (Serovich, 2001). The Positive Malaysian Treatment Access & Advocacy Group (2012) revealed PLHIV disclosed their HIV status to the people closest to them or people they trusted such as their spouse, family members, other PLHIV, injecting drug partner, healthcare workers and counsellors.

In addition, Serovich (2001) described the motivation to disclose or not to disclose is determined by the possible consequences one anticipates as the result of their disclosure and PLHIV were likely to reveal their status when the benefit of disclosing outweighed the associated costs or effect. The positive outcome to the disclosure includes gaining social, emotional and financial support, greater condom use, cohabiting and having a better relationship with the partner and initiated their partner for HIV testing (Dessalegn et al., 2019). For example, Serovich et al. (2010) described HIV positive MSM experienced no regret when they told their family members about their serostatus or sexual orientation because they felt having close and supportive relationship helps to alleviate their burden. In contrast, the negative consequence of HIV disclosure includes loss of employment, rejection, discrimination, isolation by loved ones, burning of support providers and shame to oneself (Derlega et al., 2004). Nevertheless, Derlega et al. (2004) and Lee et al. (2013) described privacy, self-blame, wanting to protect the partner, shame, perceived stigma, disapproval and fear of rejection were reasons for non-disclosure. If PLHIV decide not to disclose their HIV status, they will face multiple stressors along with their life on how to manage their illness effectively without having a clear explanation of their behaviour related to HIV like hiding pills or lying to others (Lee et al., 2013).

Malaysia is a multi-ethnic and multicultural society predominantly consisting of a majority Muslim population where Islam is part of the cultural belief and is very influential in life. The difficulty to disclose HIV serostatus may be associated with the perception that some Muslims, living with HIV are God's punishment for their sinful activities and weakness in character (Syed, Syed Sulaiman, Hassali, Thiruchelvum, & Lee, 2015). Immoral activities such as abuse of the drug and having sex outside marriage which is forbidden in Islam have lead PLHIV to interpret their diagnosis within the cultural and religious framework of Islam (Barmania & Aljunid, 2016). The belief of homosexuality, MSM as well as a sexual relationship outside the wedlock is wholly forbidden in Islam. Such belief is also shared by other religions practice in Malaysia like Buddhism, Christianity and Hinduism. Besides the cultural and religious belief, the dual legal system which is the penal law and Islamic law (Shariah) also consider engage in sex work, cross-dressing and men engaging in sex with men as a criminal offence (Barmania & Aljunid, 2016). In many ways, the issues described are also faced in other Muslim countries where cultural and religious belief contribute to disclosure stigma (Maulana, Krumeich, & Van Den Borne, 2009).

The least affected stigma in this study was in the negative self-image domain (internalised stigma). Internalised stigma was defined as the product of internalisation of shame, blame, guilt, hopelessness, and fear of discrimination associated with being PLHIV (Hasan et al., 2012) and fear of being stigmatised, inferiority complex and experience of guilt (Abdul Bari & Aida, 2017). Interestingly, the respondents reported high perceived stigma but low internalised stigma. This may suggest that, despite the high perceived stigma reported by respondents, in reality, they did not experience actual stigma related negative consequences such as isolation, loss of employment, or poor treatment from others.

Our study findings suggest that tertiary education may serve as a protective factor against perceived stigma. This is contrary to Li & Sheng (2014) in China, where respondents with higher education level found to experience a higher level of perceived stigma. Overall, the respondents with tertiary education have a lower personalised stigma, negative self-image and perceived public stigma compared to non-tertiary education PLHIV. Our findings may explain the likelihood of people with higher educational attainment have a more enlightened attitude towards the disease (Osei-

Yeboah et al., 2017). Additionally, higher levels of education maybe associated with better communication skills and social support, which facilitate emotional support and enable them to overcome stigma better (Da Silva et al., 2013).

Our findings suggest that higher stigma reported among PWID and MSM. Findings are consistent with Phoenix and Charlson (2017), which reported those acquired HIV through heterosexual or MSM, reported negative feelings of shame and guilt and a higher level of self-stigmatisation. Specifically, Zhang et al. (2016) reported that people who get infected via injecting drug use had the worst stigma scores on perceived stigma, internalised and enacted stigma compared to their those who were infected via other routes of transmission. Those infected via injecting drug use also experienced worse emotional, physical and financial constraints were considered to suffer from "double curses" because they are both HIV carriers and injecting drug user.

As for MSM with HIV, Feng, Wu, & Detels (2010) described the source of the stigma that is not limited to MSM risk behaviour itself is perceived as a deviant behaviour from the societies expectation and their family but also within the MSM community itself. They expressed fear of being socially ostracised if their sexual orientation were disclosed.

5.6 Association Between Psychological Distress (Depression, Anxiety and Stress) and Quality of Life

The current study showed that 48.7% of respondents had depression, 58.4% anxiety and 30.5% stress. This is a threefold greater prevalence of depression, anxiety and stress reported in the general population (Institute for Public Health, 2015). Globally, the prevalence of depression and anxiety in PLHIV ranges from 7.2% to 71.9% and 4.5% to 82.3%, respectively (Olagunju et al., 2012). Variation of depression, anxiety and stress prevalence reported among PLHIV may be due to different study instruments and methodological approaches used (Chaudhury, Bakhla, & Saini, 2016). Despite that, when comparison of prevalence was done with similar studies using DASS and HIV populations, the prevalence of current study showed higher prevalence compared to another study (28% depression, 6% anxiety and 2% stress) conducted in a less affluent state, Kelantan (Othman et al. (2015). MSM in the current study reported significantly higher DASS compared to PWID. We hypothesised that the discrepancy found on the depression, anxiety and stress prevalence was because most Kelantan respondents were PWID, while the majority of respondents in the current study were MSM. Tao et al. (2017) found a similar trend and postulated that depression among MSM in China is higher because they are vulnerable, where they experience HIV-related social isolation and stigma.

The prevalence of depression, anxiety and stress in this study were highest reported when compared to all clinical groups identified in Malaysia (post-stroke, postnatal mothers, headache and breast cancer) (Hatim, Zainal, Sin, & Tan, 2002; Parsons, Young, Rochat, Kringelbach, & Stein, 2012). According to Mukhtar & Oei (2011), the prevalence of depression in clinical groups ranges from 3.9% to 46% in Malaysia. Studies of depression in clinical groups, especially PLHIV, is important since PLHIV may suffer from depression any time before, after or during the adjustment of their illness apart from having a physical illness. This is an important indicator for clinicians and physicians of which they should assess and monitor not only the biological state but also the psychological state of patients.

The association between depression and HIV could be explained by the complex relationship exists. Depression was described as both a risk factor to get HIV and can be a consequence of HIV infection (Chaudhury and Bakhla, 2016). Paulina Bravo (2010) further explained where PLHIV face key decisions in their life, for examples on disclosing their HIV status, sexual relationship and parenthood which decisions of these problems were often associated or resulted in self-isolation and mental illnesses such as depression or anxiety.

Predictors of depression among PLHIV include stress, dissatisfaction with a life situation, poor health, non-adherence to antiretroviral treatment, previous history of psychiatric treatment and alcohol abuse (Chaudhury and Bakhla, 2016). This study found unemployment to be associated with depression. Bernard, Dabis, & De Rekeneire (2017) reported that unemployment predisposed PLHIV to three times the risk of having severe depression. Economic insecurity as a result of employment leads to frustration and dysfunctional family life and feeling of worthlessness, which may present as a depressive mood disorder (Kibera and Kuria, 2018).

The present study showed the protective effect of HAART in reducing the risk of having anxiety and stress. This is supported by a study in Spain among 5,185 PLHIV reported significantly lower prevalence of depression among those on antiretroviral therapy (ART) compared with those who were ART naïve (Gutiérrez et al., 2014). The capacity of therapy could explain the protective effect of ART against depression in deactivating the immune system in PLHIV, reducing cytokine levels and immune cell activation (Nanni, Caruso, Mitchell, Meggiolaro, & Grassi, 2015). Vice versa, a psychological disturbance may also lead to poor adherence to ART treatment (Tao, Qian, et al., 2017). A study among 228 MSM in China showed depression and anxiety are both risk factors for imperfect ART adherence. However, the direction of the association between HAART and psychological distress in this study cannot be determined due to the study design.

The current study demonstrates a higher stress level among those with tertiary education. This may explain by those with tertiary education were having a higher economic and social status, which predispose them to significant higher life stressor and affect their mental health status (Fang et al., 2016).

Depression, anxiety and stress were significantly having a negative impact on QOL of respondents. These findings were in agreement with the previous study by Mutabazi-Mwesigire et al. (2015a) in Uganda, three studies in Nigeria by Olisah & Adekeye (2014) and by Wakawa et al. (2014;) and Musa et al. (2014), in Brazil by Betancur, Lins, Oliveira, & Brites (2017), Adeoti, Dada, & Fadare (2018) and Olagunju et al.)2012) in Nigeria and Fincham, Smit, Carey, Stein, & Seedat (2008) in South Africa reported association between anxiety and QOL. A systematic review with respect to the relationship between depression and QOL among PLHIV was reported by Hartzell, Janke, & Weintrob (2008).

5.7 Association Between Stigma and Psychological Distress (Depression, Anxiety and Stress)

This study showed that all stigma domains were associated with higher odds of depression and anxiety, while the disclosure concern domain was associated with higher odds of stress. The findings from the current study confirmed a significant negative association between stigma with depression, anxiety and stress. This was consistent with many studies in the region which supported the negative impact of HIV-related stigma on psychological distress in Thailand (Li, Lee, Thammawijaya, Jiraphongsa, & Rotheram-Borus, 2009), in New York (Porter et al., 2015), in Uganda (Ashaba et al., 2018; Okello et al., 2015), in India (Chan et al., 2017), in China (Wang et al., 2017b), in Cambodia (Yi et al., 2015b). The meta-analysis by Pascoe & Smart Richman (2009) described significant negative effect of perceived stigma on both mental and physical health and the study also concluded that individuals who experience chronic stigma are vulnerable to poor mental health including anxiety, stress and depression.

Internalised stigma and perceived stigma has been associated with depression when a person absorbs stigmatising assumptions and stereotypes related to HIV in which they come to believe and apply it to themselves (Chan et al., 2017; Drapalski et al., 2013; Li et al., 2009; Wang et al., 2017). Stigma may discourage them from disclosing HIV status and prevent them from seeking help from their close partners, family members or friends, which make them prone to have depression (Wang et al., 2017). Even in the absence of any discrimination, stigma may have a negative impact on the self-concept and actions of stigmatised people where they were expecting to be stigmatised or discriminated may cause social withdrawal and consequent disadvantages (Deacon, 2006).

Li et al. (2009) describe that PLHIV with depression must cope with the double stigma of HIV and mental illness. Stigma prevents PLHIV from seeking and receiving social support from others, which then leads them to depression and may, in turn, create more isolation, discourage treatment adherence and leads to deterioration of their health. Okello et al. (2015) described depression as an indicator for psychological distress and those who preferred to keep secret their HIV status from most people had higher internalised HIV stigma and depression and were more likely to be clinically depressed.

5.8 Limitations of the Study

To understand the results and conclusion of this study, certain limitations need to be considered when interpreting the research findings.

5.8.1 Confounders

This was an observational cross-sectional study. The best effort has been taken to measure the possible confounders in this study. In this study, age, gender, marital status, ethnicity, education level, income, employment status, mode of transmission, co-infection, CD4 level, ART therapy and survey centres were adjusted in the statistical analysis. However, there are possible confounders which were not measured in this study. Sign and symptoms which may be a source of confounding were not measured in this study. Symptoms management for a PLHIV is recognised as an important component in HIV care management (Holzemer et al., 2001). This includes the clinical progression parameters in patients starting ART and the sign and symptom checklist of persons with HIV disease (SSC-HIV). The checklist was designed to assess the intensity of HIV with six symptoms clusters estimates to measure the patients self-reported of HIV-related signs and symptoms which includes nausea, vomiting, malaise, weakness, fatigue, confusion or distress, fever/chills, gastrointestinal discomfort and shortness of breath (Holzemer et al., 2001). Gakhar and colleagues (2013) reported that PLHIV with diarrhoea symptom scored significantly lower than the controls in all QOL domains except cognitive functioning and mental health.

The association between antiretroviral therapy (ART) side effects has not been consistently reported. As patients live longer with HIV, AIDS-related complications, and the side effects of HIV medication lead to significantly poorer QOL (Gakhar et al., 2013). ART side effects are one of the primary reasons causing PLHIV to delay or stop taking live-saving medication. Therefore clinical intervention is critically needed to assist PLHIV in managing ART side effects (Chen et al., 2013). The ART side effects and its impact on QOL have not been assessed in this study and may be a confounder.

5.8.2 Bias

5.8.2.1 Sampling Bias

The participants in this study were recruited via universal sampling. Every PLHIV attended the HIV clinic session was approached to participate through the attending physician and had an equal chance to get involved in the study. In the current study, the response rate was very low range from 14.5% in UMMC and 17.5% in Tanglin clinic. The low response rate was compounded by the fact that the interview was carried out in the clinic setting where patients were unwilling to spend extra time answering the questionnaire. The low response rate was reported in both survey centres because data collection was interview based. Each respondent took a minimum of 20 minutes, and some took more than 1 hour per interview session when respondents needed more time to discuss issues concerned related to HIV and their health. The majority of non-respondents PLHIV were those who could not wait for the interview session due to their time constraints and commitment.

The current study involved PLHIV and sensitive topics like substance abuse, sexual behaviour and voluntary subject participation, which is particularly vulnerable to sampling bias (Cheung et al., 2017). Those who choose to participate in the study might be possible those with a more positive view towards themselves (Phoenix and Charlson, 2017) while those who did not choose to participate are possibly the hardest study participation whom more likely to report risk behaviour and were potential to leads to risk factor underestimation (Cheung et al., 2017).

The respondents were PLHIV who are quite healthy and well enough to attend the clinic session as compared to PLHIV who were unwell or being admitted to the ward. The group of PLHIV in the current study might show a different rate of QOL as compared to those who are unwell and not in the study. The gender ratio of respondents in this study did not reflect the ratio of HIV-infected persons as reported by the Ministry of Health census. This study showed male to female ratio (11:1), which is higher than the Malaysia HIV cases ratio in the year 2015, which was (4:1). Gender difference in QOL, psychological distress and stigma were unable to be demonstrated due to the small number of female respondents.

5.8.2.2 Measurement Bias

As the interview was conducted face-to-face, participants may not have been honest in reporting their actual practices due to social desirability (Van De Mortel & Van De Mortel Rn, 2008). Social desirability is the tendency for respondents to present a favourable image of themselves. The method of question administration via face-to-face ensures more item response, higher response rate and lower cognitive burden. In this study, the interviewers were briefed and trained on how to carry out the interview (e.g. non-leading answers, reading the words from the questionnaire accurately). This was done to reduce interviewer bias.

5.8.3 Study Design

This study was a cross-sectional design where it is only a ‘snapshot’ of the study outcome and the characteristics associated with it is only for a specific point in time where the situation may provide differing results if another time-frame had been chosen. The disadvantages of a cross-sectional study are the difficulty to make a causal inference from the study (Levin, 2006). However, in this study, a cross-sectional design allows lesser time and resources to conduct the study, enabled many variables to be assessed simultaneously and no loss to follow up. The cross-sectional study can also be used to generate hypotheses and ideas for possible research areas in the future using more vigorous study design (Goldberg, McManus, & Allison, 2013).

5.8.4 Generalisability

This study involved PLHIV recruited from the government health clinic, tertiary level hospital and CBOs in the Federal Territory of Kuala Lumpur. Thus, the findings may not be generalised to the entire HIV population in Malaysia.

CHAPTER 6: CONCLUSION

6.1 Chapter Overview

As outlined in the earlier chapters of this thesis, the main aim of the study was to measure the quality of life, stigma and psychological distress (depression, anxiety, stress) among PLHIV in the Federal Territory of Kuala Lumpur. This chapter summarises the main findings of the study, discusses the public health significance and issues central to the study and recommendations for possible research areas in the future.

6.2 Summary of Findings

Quality of life of PLHIV in Kuala Lumpur was moderate with good scores in psychological and physical domains. The most affected QOL domains with the lowest scores were social relationship domain and spirituality, religion and personal belief domain, suggesting that participants may perceive that they have a poor personal relationship with others and did not receive adequate social support.

There was a moderate level of stigma among PLHIV in Kuala Lumpur with disclosure concerns is the biggest stigma which may be contributed by cultural and religious belief. The least affected stigma was negative self-image where PLHIV did not experience actual stigma related negative consequences in actual life. This study also demonstrates an inverse association between stigma with QOL among PLHIV.

The psychological distress among PLHIV in Kuala Lumpur was prevalent with higher prevalence of depression, anxiety and stress reported in the Malaysia general population with 48.7%, 58.4% and 30.5% respectively. Those having severe depression, severe anxiety and severe stress were having significantly lower odds of good QOL.

Finally, this study demonstrates the positive association between stigma and psychological distress (depression, anxiety and stress) of PLHIV. Personalised stigma, negative self-stigma and personal public attitude stigma were associated with higher odds of having depression and anxiety among PLHIV. Those with disclosure concern stigma have higher odds of stress.

6.3 Public Health Significance

Malaysia's commitment to addressing HIV issues in the country are detailed in the National Strategic Plan for Ending AIDS 2016-2030. One strategy to ending AIDS by 2030 is to achieve 95% of PLHIV were placed on antiretroviral treatment. This strategy is mainly supported by the provision of free HAART and follow up services in all 141 government hospitals and health clinics nationwide. Furthermore, government policy in integrating HIV management into the Primary Healthcare makes HIV services accessible, acceptable, affordable and promote better uptake of HIV testing, care and treatment to the whole community. The current study demonstrates PLHIV on HAART, and regular HIV clinic follow up were having a good quality of life compared to those who are not on such treatment. This not only confirms that Malaysia is doing the right measures, but it provides solid evidence which inspires policymakers for the scaling up of the HIV treatment centres, as well as making HIV treatment more accessible.

A significant relationship was found between education level, employed and quality of life among respondents in the current study. Since PLHIV find it difficult to get and keep jobs, an initiative to provide job opportunities and financial assistance for PLHIV are interventions leading to better promotion of quality of life. This can be achieved by having inter-agency collaboration between government agencies, civil society and the private sector to create an effective intervention in fighting HIV and AIDS.

For healthcare professionals, the study findings highlight the importance of QOL assessment among PLHIV. It is recommended to conduct a regular assessment using a good self-rated QOL instrument which could significantly help to identify the most crucial domains in individual's life and allow healthcare providers to prescribe more specific and better care for PLHIV under their care. The selection of QOL measures to be used in busy HIV clinic is likely to be influenced by the purpose of QOL assessment, acceptable by patients and clinicians in the HIV clinic setting and proven to be the most cross-culturally valid (Cooper et al., 2017).

This study identified stigma and psychological distress (depression, anxiety and stress) as gaps in achieving a good quality of life among PLHIV. The relationship between stigma with psychological distress in the current study was consistent with other studies that conceptualise stigma and discrimination as a stressor. HIV-related stigma has been long regarded as a hindrance to public health effort in curbing HIV. Therefore, efforts to reduce stigma and discrimination among PLHIV are highly warranted. There are various ways in which HIV stigma can be reduced. The highest priority in HIV stigma reduction is the need to better educate PLHIV and the public to address misconceptions about HIV. Misrepresentation of HIV due to inaccurate and biased information presented by the media has framed HIV as negative deadly disease with no treatment. Therefore, the media plays an important role in delivering nonbiased messages about HIV and stop giving negative representation and stereotypes attached to PLHIV. Healthcare professionals should work with media to disseminate well accurate information about HIV on the fact that HIV has been transformed into chronic illness with the availability of HAART treatment to the public. Furthermore, it is important to intensify education activities among healthcare professionals since discrimination, and social rejections are also originated from them. Education plays important roles in reducing social anxiety towards HIV and therefore, will increase empathy towards those living with HIV rather than assigning stigma. Thus, it is also important to enact policies that protect the safety and health of patients and healthcare professionals in order to prevent discrimination against PLHIV.

The current study identified that stigma related to disclosure concerns is the highest form of perceived stigma among PLHIV. Self-disclosure can be improved by making disclosure safer. Safe disclosure can be promoted through peer support groups which deliver outreach activities to HIV hospital and clinic clients by giving information on treatment, adherence, emotional management and healthy living. Peer support group complement services given by the hospital ensure the continuum of care as well as adherence to treatment. It also improves the networking between social, health services and other agencies at the community level. Therefore, the existing government-funded Treatment and Adherence Support Programme (TAPs) coordinated by the Malaysian AIDS Council (MAC) need to be strengthened to reduce disclosure stigma among PLHIV. Despite that, PLHIV with greater support will also improve accessibility to health services and better adherence to treatment, which leads to good quality of life.

This study also showed low spirituality/religion and personal belief domain of quality of life, which suggest a possible benefit of spiritual/religious approach in the management of PLHIV. The involvement of religious leaders (e.g. Islamic Religious Department and Interfaith Organisations) in awareness programmes and providing psychosocial and spiritual support have successfully promoted positive behaviour change, provide guidance and motivation using a religious approach for PLHIV to face life challenges. The active role and participation of the religious leaders will help to eliminate stigma and discrimination among them and the surrounding communities, which enable to maintain a positive environment. Finally, measures to address HIV-related stigma include activities involving individual or group counselling, cognitive behavioural therapy, social support and empowerment of PLHIV to increase accessibility and availability of care and support. The comprehensive response towards HIV stigma should also take into consideration local societal values, and cultural and religious belief to be acceptable and successful.

The high prevalence of depression, anxiety and stress among PLHIV in the current study is an alarming indication that more attention should be given to the psychological distress of this group to alleviate their suffering. Thus, attention should be directed towards clinical surveillance and mental health screening using culturally accepted validated tools to diagnosed mental health issues among PLHIV. This study also highlighted the importance of having an integrated HIV clinic with mental health intervention for this vulnerable group of patients. There should be enough medical professional and healthcare workers trained in mental health. Clinicians should give close attention to help PLHIV increase their self-esteem, facilitate social support, give psycho education emphasising adaptive coping strategies and help to deal with stigma and discrimination in the community. Programme development to improve the psychological distress of PLHIV should address HIV-related stigma as a risk factor and social support for PLHIV as a protective factor and incorporate both components in the patient's management as suggested by Li et al. (2009).

6.4 Recommendations for Future Research

Based on the insight gained from this study, several recommendations are worth considering as follows:

1. Study design – further investigation on the same topic should be done. Instead of a cross-sectional study, a longitudinal study should be performed. Measurement of mental health status and other types of stigma, specifically among PLHIV should be compared. Furthermore, other factors such as assessment of the bio-clinical markers, treatment compliance, opportunistic infection monitoring, and clinical assessment should be included in the study.
2. Study population – further study to be conducted on a bigger scale nationwide for generalizability of the finding of the study.

3. Questionnaire design – further study should be performed using a structured, simplified self-administered questionnaire to screen psychological distress and stigma among PLHIV at the community level and clinic setting.
4. Stigma assessment among PLHIV, the evaluation of stigma among healthcare workers and the formulation of interventions to reduce stigma. HIV-related stigma affects the utilisation of preventive health facilities and hindered effective utilisation of healthcare services. Thus, there is an urgent need to address stigma related to disclosure among PLHIV to achieve effective utilisation of health services.

6.5 Conclusion

This study found that quality of life of PLHIV in the Federal Territory of Kuala Lumpur was low to moderate. Stigma was prevalent among PLHIV with disclosure concern as the most important form of stigma. The high prevalence of depression and anxiety is worrying as it was significantly associated with poor quality of life and closely related to higher perceived stigma and discrimination among PLHIV. It is hoped that the current study findings will contribute to the improvement of care given to PLHIV, thus preventing complications associated and eventually improve the quality of life of PLHIV in Malaysia.

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