Characteristics and Quality of Life Among People Living with HIV at Drop-in Centres and Shelter Homes in Malaysia

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ABSTRACT

Purpose: *The aim of the study was to examine whether there are any significant differences in demographic characteristics and health-related Quality of Life (QoL) among people living with HIV (PLWH) at shelter homes and drop-in centres in Malaysia.*

Method: *117 PLWH were recruited by using the purposive sampling method. Data were collected through a questionnaire survey.*

Results: *Significant differences were found between PLWH at shelter homes and drop-in centres, in their demographic characteristics and in the 3 factors in the HIV/AIDS-Targeted Quality of Life Instruments (HAT-QoL) – namely, overall function, health worries, and provider trust.*

Conclusion: *Due to the differences in characteristics and QoL among PLWH in these two settings, different approaches are suggested to assist PLWH from shelter homes and drop-in centres.*

Key words: *HIV, HAT-QoL, shelter homes, drop-in centres, Malaysia*

INTRODUCTION

In 2012, the estimated number of people living with HIV globally was approximately 32.2-38.8 million. The new infection rate has declined from 3.4 million cases in 2001 to about 2.3 million cases in 2012. Due to the antiretroviral treatment, AIDS-related deaths have also declined from approximately 2.3 million cases in 2005 to about 1.7 million cases in 2011 (Joint United Nations Programme on HIV/AIDS, 2013).

The first case of HIV in Malaysia was reported in 1986. It was estimated that there were a total of 94,841 HIV infections, 17686 AIDS cases, and 14986 AIDS-related

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deaths in Malaysia (Ministry of Health Malaysia, 2012). In 2011, the incidence rate of HIV infection among adults between 15-49 years of age has been decreasing. It is now 26% - 49% less than in 2001. Nonetheless, the mortality rate among PLWH in 2011 has remained unchanged or decreased less than 25% than in 2005. This could be related to the fact that only 20% -39% of eligible people receive antiretroviral therapy (Joint United Nations Programme on HIV/AIDS, 2013). The most-at-risk populations were drug users, commercial sex workers and the transgender population (Ministry of Health Malaysia, 2012).

The patterns of HIV transmission were relevant to the geographic regions in Malaysia. Most PLWH in the eastern regions were infected by sharing drug needles, while most PLWH in the central, northern and southern regions were infected by unsafe sex. About 90% of PLWH were males. However, the trend of female to male ratio has increased from 1: 99 in 1990 to 1: 4 in 2011. Also, the trend of sexual transmission of HIV among injecting drug users has increased from 1: 9 in 1990 to 1: 1 in 2010. Nonetheless, it is acknowledged that there is an overlap between drug addiction and those involved in sex trade, as drug users may be involved in commercial sex to get money to buy drugs (Ministry of Health Malaysia, 2012). The prevalence of HIV infection among people who inject drugs versus the general population in Malaysia was found to be higher than among sex workers or homosexuals versus the general population. Therefore, Malaysia has 75%-100% coverage for an HIV prevention programme for drug users (Joint United Nations Programme on HIV/AIDS, 2013).

Shelter homes and drop-in centres have been set up in Malaysia to provide care and support services for PLWH and other affected persons. There are 16 shelter homes for women and children that were funded by the Ministry of Women, Family and Community Development in 2011 (Ministry of Health Malaysia, 2012). The shelter homes serve the function of half-way homes that provide proper care to the homeless and abandoned PLWH. They provide follow-up support and service that hospitals may not able to offer, such as psychosocial support and treatment education. PLWH will be sent back to the community after they have recovered.

In contrast, the drop-in centres function as an extension of outreach activities. Different drop-in centres provide services to a certain targeted population, such as commercial sex workers and some injecting drug users. The drop-in centres offer basic healthcare, warm meals, peer education, and support groups as well as referrals for voluntary HIV counselling, testing, and legal aid (Malaysia AIDS

Council, n.d.). Due to the different functions of the drop-in centres and shelter homes, the QoL of PLWH in these two service providers can be quite different.

Cella and Bonomi (1995) defined health-related quality of life (HRQL) as the extent to which one's usual or expected physical, emotional, and social health are affected by a medical condition or its treatment. With the success of the HAART treatment in reducing the mortality rate of PLWH, researchers and clinicians pay attention to improving the quality of life of this population(Miners et al, 2001; Westburg and Guindon, 2004). Some QoL measurements have been developed, such as Sickness Impact Profile (SIP), Quality of Well Being Scale (QWBS), Medical Outcomes HIV Health Survey (MOS-HIV), HIV-QOL Questionnaire (HIV-QL31), HIV/AIDS Targeted Quality of Life (HAT-QoL) and Multidimensional Quality of Life Questionnaire for HIV/AIDS (MQOL-HIV) (Clayson et al, 2006). In this study, the HAT-QoL was chosen since it is a QoL measurement that has been developed and targeted at PLWH (Holmes and Shea, 1999).

Studies have found good correlations between similar dimensions in HAT-QoL and MOSHIV (Taylor et al, 2009) and in HAT-QoL and SF-36(Holmes et al, 2007). Some studies have figured out the relationship between poor HAT-QoL and depression, personality disorder, and physical symptoms (Gore-Felton et al, 2006; Lorenz et al, 2006; Hansen et al, 2009).

The authors of this article are not aware of any study that compares the key characteristics and the QoL of PLWH at drop-in centres and shelter homes in Malaysia. The comparisons are important, as the identification of key characteristics and QoL differences among PLWH at drop-in centres and shelter homes may enable programme developers to better tailor services to improve the QoL of PLWH at their drop-in centres or shelter homes.

Objectives

The aims of this study were:

1. To attempt a socio-demographic profile of PLWH in shelter homes and those visiting drop-in centres;
2. To discover differences (if any) in the patterns of QoL between PLWH in shelter homes and those visiting drop-in centres; and,
3. To establish if there is any significant association between the socio-demographic profile and QoL of PLWH in shelter homes and those visiting drop-in centres.

METHOD

Participants

117 PLWH from 5 non-governmental organisations (NGOs) in Malaysia were invited to participate in this study. Through the purposive sampling method, only those PLWH who stayed at shelter homes or visited the drop-in centres were included. About 42% were from HIV shelter homes and about 58% were from drop-in centres. The age range was 17 -70 years (M = 40.25, SD = 11.57). Most of the participants (78.6%) were under medication adherence, 74.8% were males, 69% were already married or in a relationship, 64% had not had a sexual partner in the past 3 months, 63.3% were unemployed or housewives, 60.9% were living with friends, and 54% were Malay (see Table 1).

Table 1: Demographic Characteristics of Participants

Centres	Drop-in	42.7% (50)	Ethnicity	Malay	54.3% (63)
	Shelter home	57.3% (67)		Chinese	29.3% (34)
				Others	16.4% (19)
Gender	Male	74.8% (86)			
	Female	25.2% (29)	Religion	Muslim	59.8% (67)
				Others	40.2% (45)
Age	40 or below	50.4% (59)			
	above 40	49.6% (58)	HIV duration	60 months or below	47.9% (56)
				above 60 months	52.1% (61)
Employment	Employed	37.7% (43)			
	Housewife or Unemployed	63.3% (71)	Relationship	Single, divorced or widowed	31% (36)
				Married or in a relationship	69% (80)
Living	Alone	11.3% (13)			
Arrangement	With family	27% (31)	Drug-addict	Yes	24.1% (31)
	With friends	60.9% (70)		No	75.9% (84)

Sexual	Heterosexual	48.4% (44)	Commercial	Yes	6.1% (7)
Orientation	Homosexual	40.7% (37)	sex workers	No	93.9% (107)
	Bisexual	11.0% (10)			
Medical	Yes	78.6% (92)	Sexual	None	64% (71)
Adherence	No	21.4% (25)	partners in the	One	18% (20)
			past 3 months	More than one	18% (20)

Note: Number in bracket indicates the number of respondents

Questionnaire

Demographic Information

In this section, participants were asked to fill in some information that was relevant to their backgrounds, such as gender, education, and employment status.

HAT-QoL

The HAT-QoL scale includes 34 items and measures 9 dimensions, which are overall function (6 items), life satisfaction (4 items), health worries (4 items), financial worries (3 items), medication worries (5 items), HIV mastery (2 items), disclosure worries (5 items), feelings about doctors or provider's trust (3 items), and sexual functions (2 items). Participants needed to circle a number from 1 to 5 to indicate how often they have had such feelings in the past 4 weeks. Scores on each subscale were recorded on a scale from 0 to 100. A higher score indicated a better QoL (Holmes and Shea, 1997, 1998, 1999; Holmes et al, 2007; Holmes and Ruocco, 2008). The Cronbach Alpha reliabilities of the 9 dimensions were found to be higher than 0.8 (Holmes and Ruocco, 2008).

Procedure

Through the internet and introductions to workers at NGOs, the authors contacted some NGOs that provide services to PLWH for permission to conduct this study. The NGOs were provided with the study proposal, a sample of the informed consent form for PLWH and a sample of the questionnaire. Permission was obtained from 5 NGOs that are located at two different states in Malaysia: 1 in Penang and 4 in Selangor. Thereafter, the authors employed the purposive sampling method to recruit PLWH participants who were clients of drop-

in centres or shelter homes. Purposive sampling is a type of non-probability sampling method where sample selection is based on the fit of the sample with the purpose of the study, with special inclusion and exclusion criteria (Daniel, 2011). In this study, only those PLWH who either stayed at shelter homes or visited the drop-in centres were recruited.

The exploratory cross-sectional survey-based research design was adopted in this study. All PLWH at the NGOs were briefed about the aims of this study and their right not to participate. Only those who agreed to participate and signed the informed consent form were recruited. Questionnaires were then distributed to participants. Researchers or the contact persons of the NGOs stayed to assist the participants with any problems which might occur while they were answering the questionnaires. A token was given to participants after they completed the questionnaires.

RESULTS

Differences between Demographic Characteristics of Participants from the HIV shelter homes and drop-in centres

The demographic backgrounds of participants from the HIV shelter homes and drop-in centres were different. The results of **Chi-square test for independence** showed that most participants from the HIV shelter homes were drug users, heterosexual, under medication, older, non-Malays, non-Muslim, unemployed, had been diagnosed as a PLWH for a longer period and were not staying with family (see Table 2).

Table 2: Differences between Characteristics of PLWH in HIV shelter homes and drop-in centres

Characteristics		Drop-in Centre (n) (%)	Shelter Home (n) (%)	Chi-square	df	Total n	p-value
Drug User	Yes	3 (6.1)	28 (41.8)	19.61	1	115	<0.001
	No	46 (93.9)	38 (56.7)				
Sexual	Heterosexual	6 (16.7)	38 (69.1)	23.95	1	91	<0.001
Orientation	Homosexual or Bisexual	30 (83.3)	17 (30.9)				

Medical	Yes	33 (66)	59 (88.1)	8.29	1	117	0.004
Adherence	No	17 (34)	8 (11.9)				
Age	40 or below	37 (74)	22 (32.8)	19.41	1	117	<0.001
	Above 40	13 (26)	45 (67.2)				
Ethnicity	Malay	37 (75.5)	26 (38.8)	15.37	1	116	<0.001
	Non-Malay	12 (24.5)	41 (61.2)				
Religion	Muslim	38 (80.9)	29 (44.6)	14.91	1	112	<0.001
	Non-Muslim	9 (19.1)	36 (55.4)				
Employment	Employed (Full/Part time)	31 (66)	12 (17.9)	27.15	1	114	<0.001
Status	Unemployed	16 (34)	55 (82.1)				
Diagnosis	60 months or below	34 (68)	22 (32.8)	14.19	1	117	<0.001
	Above 60 months	16 (32)	45 (67.2)				
Residence	With family	18 (37.5)	13 (19.7)	4.45	1	114	0.035
	Single or with friends	30 (62.5)	53 (80.3)				

HAT-QoL

There were significant differences between HAT-QoL of participants from drop-in centres and those from shelter homes. The results of **t-test for independent sample means** found that participants from the drop-in centres have lower provider trust and health worries, but have higher overall function than those from shelter homes (see Table 3).

Table 3: Comparisons of HAT-QoL of PLWH at drop-in centres and shelter homes

HRQL	Location	M	SD	t	df	p-value
Overall function	Drop-in centre	63.59	19.61	2.53	115	0.013
	Shelter home	52.96	24.41			
Life satisfaction	Drop-in centre	64.38	19.41	1.29	114	0.201
	Shelter home	58.81	25.52			
Health worries	Drop-in centre	60.88	29.09	2.13	114	0.035
	Shelter home	49.53	27.83			
Financial worries	Drop-in centre	52.04	28.84	-1.58	113	0.117
	Shelter home	60.61	28.74			
Medication worries	Drop-in centre	74.58	24.98	0.91	91	0.364
	Shelter home	69.32	27.44			
HIV mastery	Drop-in centre	57.38	31.48	-0.18	112.61	0.858
	Shelter home	58.52	37.29			
Disclosure worries	Drop-in centre	45.04	38.21	-1.94	114	0.055
	Shelter home	57.08	28.76			
Provider trust	Drop-in centre	59.72	24.93	-4.54	114	0.001
	Shelter home	78.79	19.89			
Sexual function	Drop-in centre	79.51	23.39	1.69	109.95	0.094
	Shelter home	70.31	34.54			

Associations between HAT-QoL and Demographic backgrounds

The authors examined whether or not the 3 factors of HAT-QoL (overall function, health worries, and provider trust) were significantly associated with the demographic variables that have been found to differ between the two settings. The 3 HAT-QoL factors were categorised into two groups each by using their median score, and then the **Chi-square test for independence** was used to find the associations. Firstly, the overall functions of participants who were 40 years old or below, were better than those who were above 40 years (64.2% vs. 38.8%), $X2$ (1, $n = 102$) = 6.57, $p = 0.011$. Secondly, participants who were homosexual or bisexual and were employed, had more health worries than those who were heterosexual (65.2% vs. 43.2%), $X2$ (1, $n = 90$) = 4.41, $p = 0.036$, and were unemployed (64.3% vs. 39.4%), $X2$ (1, $n = 113$) = 6.52, $p = 0.011$. Lastly, the participants who were drug users, aged above 40, unemployed, and diagnosed as PLWH for more than 60

months, had higher provider trust than those who were non-drug users (56.7% vs. 20.7%), X2 (1, n = 112) = 15.52, p = 0.001; aged 40 or below (41.4% vs. 21.4%), X2 (1, n = 114) = 5.25, p = 0.022; employed (38% vs. 15%), X2 (1, n = 111) = 6.49, p = 0.011; and diagnosed as PLWH for less than 60 months (42.6% vs. 18.9%), X2 (1, n = 114) = 7.41, p = 0.006 (see Table 4).

Table 4: The associations between Demographic Characteristics and the 3 HAT-QoL factors

Demographic Characteristics		Overall Function (n) (%)		Health Worries (n) (%)		Provider Trust (n) (%)	
		Below median	Above median	Below median	Above median	Below median	Above median
Drug User	Yes	14 (56)	11 (44.1)	16 (53.3)	14 (46.7)	13 (43.3)	17 (56.7)***
	No	34 (45.3)	41 (54.7)	43 (51.2)	41 (48.8)	65 (79.3)	17 (20.7)
Sexual	Heterosexual	18 (47.3)	20 (52.6)	25 (56.8)	19 (43.2)*	31 (70.5)	13 (29.5)
Orientation	Homosexual or Bisexual	15 (36.6)	26 (63.4)	16 (34.8)	30 (65.2)	32 (72.7)	12 (27.3)
Medical	Yes	40 (51.3)	38 (48.7)	49 (53.3)	43 (46.7)	60 (65.2)	32 (34.8)
Adherence	No	9 (37.5)	15 (62.5)	11 (45.8)	13 (54.2)	18 (81.8)	4 (18.2)
Age	40 or below	19 (35.8)	34 (64.2)*	26 (44.8)	32 (55.2)	44 (78.6)	12 (21.4)*
	Above 40	30 (61.2)	19 (38.8)	34 (58.6)	24 (41.4)	34 (58.6)	24 (41.4)
Ethnicity	Malay	27 (48.2)	29 (51.8)	30 (48.4)	32 (51.6)	44 (73.3)	16 (26.7)
	Non-Malay	21 (46.7)	24 (53.3)	29 (54.7)	24 (45.3)	34 (64.2)	19 (35.8)
Religion	Muslim	29 (49.2)	30 (50.8)	34 (51.5)	32 (48.5)	48 (75)	16 (25)
	Non-Muslim	16 (42.1)	22 (57.9)	22 (48.9)	23 (51.1)	28 (62.2)	17 (37.8)
Employment Status	Employed (Full/Part time)	15 (37.5)	25 (62.5)	15 (35.7)	27 (64.3)*	34 (85)	6 (15)*
	Unemployed or Housewives	32 (54.2)	27 (45.8)	43 (60.6)	28 (39.4)	44 (62)	27 (38)
Diagnosis	60 months or below	22 (44.9)	27 (55.1)	27 (49.1)	28 (50.9)	43 (81.1)	10 (18.9)**
	Above 60 months	27 (50.9)	26 (49.1)	33 (54.1)	28 (45.9)	35 (57.4)	26 (42.6)
Residence	With family	14 (51.9)	13 (48.1)	17 (54.8)	14 (45.2)	24 (77.4)	7 (22.6)
	Single or with friends	34 (47.2)	38 (52.8)	41 (50)	41 (50)	53 (66.3)	27 (33.8)

Notes: * p < 0.05** p < 0.01 *** p < 0.001

DISCUSSION

Some drop-in centres and shelter homes have been set up by the Malaysian government to serve the PLWH. Since there has been no study on the demographic characteristics and QoL among PLWH at these two different settings in Malaysia, the authors aimed to examine these issues by building a profile of the targeted population at these settings and by comparing their QoL. The results of this study may provide information to the programmers and policy makers to design effective strategies to improve the QoL of PLWH at these two different settings.

Firstly, the results confirmed differences in the targeted population that were served by drop-in centres and shelter homes. Compared to PLWH at the drop-in centres, most PLWH at the HIV shelter homes were drug users, heterosexual, under medication, older, non-Malays, non-Muslim, unemployed, had been diagnosed as PLWH for a longer period and were not staying with their families. The higher percentage of Malays at drop-in centres and the higher percentage of Chinese at shelter homes can be of relevance to the NGOs that granted permission to conduct this survey. In Malaysia, all Malays are Muslims and therefore Malay PLWH were always served by Muslim-based NGOs. In contrast, most non-Muslims, such as Chinese and Indians, were always served by non-Muslim-based NGOs. Due to the difference in religion, most Muslims and non-Muslims are allocated to different faith-based organisations on the basis of their religious beliefs (Ministry of Health Malaysia, 2012).

Besides the religious and ethnic differences, the results supported the characteristic differences between the two settings. PLWH at shelter homes were mostly those who could not take care of themselves and were abandoned by their families,older, unemployed, with a longer history of HIV, and under medication. These background differences reflect the differing target population of the drop-in centres and of the shelter homes. In other words, the results confirmed the importance of setting up these two different service providers as they cater to the needs of PLWH with different backgrounds.

Importantly, the study results showed that PLWH from the drop-in centres have lower provider trust but higher health worries and overall function than those from the shelter homes. These differences were found to be associated with some background factors. Firstly, closer examination of the associations between demographic factors and QoL suggested that drug users, unemployment, older age and long-term diagnosis are associated with better provider trust. In Malaysia,

the policy on illicit drug use is very strict (Kamarulzaman, 2009), and most PLWH faced discrimination in society since their HIV infections were usually regarded as a punishment for their sinful activities, such as drug misuse and prostitution (Hasanah et al, 2011). As most of these PLWH stayed at shelter homes, needed others to take care of them and were usually neglected or discriminated against by society for their drug use, the unconditional assistance and care given by service providers could be the reason for higher provider trust reported by PLWH at shelter homes rather than by those at drop-in centres. In other words, PLWH who stayed at shelter homes received more social support than PLWH at drop-in centres. The social support has been found to be significantly associated with QoL of PLWH (Chou et al, 2013; Kipke et al, 2013).

Secondly, health worries are associated with sexual orientation and employment status; most of the PLWH who were employed, homosexual or bisexual, had higher health worries than those who were unemployed or heterosexual. In other words, most of these PLWH are served by drop-in centres. This could be because most PLWH who were employed needed to take the initiative to care for themselves, such as how to face conflicts between healthcare and the demands of their job. In contrast, PLWH who were unemployed, generally stayed at shelter homes and did not have to handle these worries as they were cared for by workers at the shelter homes. Some studies have pointed out the significant association between employment status and QoL (Blalock et al, 2002; Rueda et al, 2011). Apart from this, the higher health worries among homosexual PLWH could be related to the higher number of their sexual partners in the past 3 months. Further analysis by the authors showed that these homosexual PLWH had more sexual partners in the past 3 months ($M = 1.93$, $SD = 2.29$) than these heterosexual PLWH ($M = 0.14$, $SD = 0.41$), $t(45.87) = 5.12$, $p = 0.001$.

Lastly, the overall function is associated with age; thus, the younger PLWH have better overall function than older PLWH. Again, most of these PLWH are served by drop-in centres. While comparing the younger and the older PLWH, the analyses of Chi-square test for independence suggested that more of the younger PLWH had a shorter period of diagnosis (57.6% vs. 37.9%, $p = 0.033$), were employed (60.3% vs. 14.3%, $p = 0.001$), were not drug-addicted (11.9% vs. 42.9%, $p = 0.001$), and were not under medical adherence (64.4% vs. 93.1%, $p = 0.001$). In other words, the overall physical and psychological condition of PLWH from drop-in centres (most of them are younger) are better than those from shelter homes, and therefore, the PLWH from drop-in centres have higher

overall function than those from shelter homes. These findings are quite similar to the findings that examine the QoL of PLWH attending HIV clinics in Malaysia (Hasanah et al, 2011).

CONCLUSION

Since the results have shown that there are significant differences between demographic backgrounds and HAT-QoL among the PLWH from drop-in centres and those from shelter homes, the findings of this study will be able to assist NGOs in designing better services to meet the needs of PLWH at the two different settings. The continuing services from both drop-in centres and shelter homes are therefore necessary, as services are provided to a different targeted population. Moreover, the authors also found differences in QoL among PLWH from drop-in centres and those from shelter homes. These differences were associated with some demographic factors. Based on the findings, it appears that different strategies are required to assist PLWH from the drop-in centres and those from shelter homes. Programmers at drop-in centres may consider implementing more strategies to improve provider trust and reduce health worries among their clients, and programmers at shelter homes may consider implementing more strategies to increase overall function among their clients.

Since most PLWH in Malaysia are allocated to different settings based on their religious beliefs, future studies could include more drop-in centres and shelter homes catering to people from different religious backgrounds. Besides, as suggested by Mprah (2013) and Shanbhag and Krishanmurthy (2012), future studies could further examine the QoL among PLWH with different disabilities at shelter homes and the QoL of caregivers or helpers at the two different settings.

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