นิพนธ์ต้นฉบับ

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การตีตรา แรงสนับสนุนทางสังคม คุณภาพชีวิตของผู้ติดเชื้อเอชไอวีและผู้ป่วยเอดส์ในจังหวัดลพบุรี

Perceived Stigma, Social Support, and Quality of Life among People Living with HIV/AIDS in Lopburi Province

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บทคัดย่อ

การศึกษาภาคตัดขวางนี้มีวัตถุประสงค์เพื่อวัดระดับการตีตรา แรงสนับสนุนทางสังคม คุณภาพชีวิตและค้นหาปัจจัยที่มีความสัมพันธ์ระหว่างปัจจัยส่วนบุคล ปัจจัยคลินิก การตีตรา แรงสนับสนุนทางสังคม กับคุณภาพชีวิตของผู้ติดเชื้อเอชไอวีและเอดส์ ณ คลินิกยาต้านไวรัสในจังหวัดลพบุรี ตั้งแต่วันที่ 15 กรกฎาคม พ.ศ.2560 ถึงวันที่ 15 มกราคม พ.ศ.2561 เลือกตัวอย่างแบบจำเพาะเจาะจงจากโรงพยาบาลของรัฐ จำนวน 6 แห่งตามสัดส่วนของผู้ติดเชื้อเอชไอวีและเอดส์ที่ขึ้นทะเบียน จากตัวอย่างทั้งสิ้น 415 ราย ยินดีเข้าร่วมการวิจัยจำนวน362 ราย (อัตราตอบรับ ร้อยละ 87.23) เก็บรวบรวมข้อมูลโดยใช้แบบสัมภาษณ์แบบมีโครงสร้างภาษาไทย ประกอบด้วย WHOQOL-BREF-HIV 31 ข้อ การรับรู้การตีตรา 22 ข้อ และ แรงสนับสนุนทางสังคม 14 ข้อ

ผลการศึกษาพบว่าร้อยละ 85 ของผู้เข้าร่วมการวิจัยมี คุณภาพชีวิตโดยรวมอยู่ในระดับสูง โดยคะแนนด้านสิ่งแวดล้อมสูงที่สุด (Mean 25.01,S.D. 4.15) ร้อยละ 9.4 มีระดับการตีตราระดับสูง โดยคะแนนด้านความรู้สึกอับอายในตนเองสูงที่สุด (Mean 14.11, S.D. 4.28) และร้อยละ 70.2 มีการสนับสนุนทางสังคมโดยรวมอยู่ในระดับสูงโดยคะแนนด้านการสนับสนุนทางด้านเครื่องมือสูงที่สุด (Mean 18.6, S.D. 4.69)การวิเคราะห์ด้วย Multivariables binary logistic regressionโดยควบคุมอิทธิพลของปัจจัยส่วนบุคล และปัจจัยคลินิกพบการถูกกีดกันทางสังคมลดระดับคุณภาพชีวิต (ORadj 0.84, 95% CI, 0.76 - 0.92) แต่การสนับสนุนทางสังคมด้านการประเมินจะเพิ่มระดับคุณภาพชีวิต (ORadj 1.89, 95% CI, 1.31 - 2.70)

การศึกษาครั้งนี้แสดงถึงผลกระทบของ การรับรู้การตีตราและการสนับสนุนทางสังคมที่มีต่อคุณภาพชีวิต ดังนั้นเพื่อพัฒนาคุณภาพชีวิตของผู้ติดเชื้อเอชไอวีและเอดส์ บุคลากรที่ดูแลคลินิกยาต้านไวรัสควรหาแนวทางส่งเสริมให้ผู้ติดเชื้อเอชไอวีและเอดส์รับรู้คุณค่าในตนและให้บริการที่เสริมแรงสนับสนุนทางสังคม และลดความรู้สึกถูกตีตราหรือเลือกปฏิบัติ

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Abstract

This cross-sectional study aimed to measure level of quality of life (QoL), social support, and perceived stigma among people living with HIV/AIDS (PLWHA) at antiretroviral clinics (ARV clinics) in the Lopburi Province, Thailand from 15 July 2018 to 15 January 2019. The PLWHA were purposively selected from six public hospitals using probability sampling proportional to population size. The data were collected by face-to-face interviews using the Thai language version of the 31- item World Health Organization Quality of Life in HIV-infected Persons instrument (WHOQOL-BREF-HIV), which is a structured questionnaire with 22 items about internalized shame and social isolation and 14 items about social support. The total scores of WHOQOL-BREF-HIV were categorized into two groups (good and poor quality of life) using the median as a cut-off-point.

Of the 415 invited PLWHA, 362 PLWHA agreed to participate (response rate = 87.2%). The results indicated that PLWHA reported good QoL (85.1%) (Mean=123.63; S.D.=15.14). About 9.4% of PLWHA reported a high level of perceived stigma, while 70.2% reported a good level of social support. Multivariate binary logistic regression revealed that social rejection was associated with reduced QoL (ORadj 0.84; 95% CI, 0.76 - 0.92), after adjusting for general characteristics and clinical factors. However, appraisal support provision of information that useful for self-evaluation purposes was associated with improved QoL (ORadj 1.89; 95% CI, 1.31 - 2.70), after adjusting for confounding.

This study emphasized the effects of perceived stigma and social support on quality of life among PLWHA. To improve QoL among PLWHA, healthcare staff at ARV clinics should consider a proactive approach to increase self-esteem, to provide service in line with social support, and to reduce perceived stigma and discrimination.

Keywords: Quality of Life, Perceive Stigma, Social Support, People Living with HIV and AIDS

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Introduction

Human immunodeficiency virus (HIV) is a crucial public health problem worldwide, In the year 2018, people living with HIV/AIDS(PLWHA) were 37.9 million worldwide and about 5.9 million were in Asia and Pacific region. (UNAIDS.org, 2019) In Asia and Pacific region, problem of HIV/AIDS has been reported in 12 countries including Thailand(UNAIDS.org). Quality of life (QoL) is 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. (The WHOQOL Group, 1994a). QoL has been widely used to measure both negative and positive aspects of life due to health status. The impacts of HIV/AIDS on physical and psychological health, social and well-being of PLWHA were reported in many countries. (Basavaraj, Navya, & Rashmi, 2010; Bello & Bello, 2013; Hou et al., 2014; Mkangara et al., 2009; Nobre, Pereira, Roine, Sintonen, & Sutinen, 2017; Nojomi, Anbary, & Ranjbar, 2008; Tran et al., 2012; Yadav, 2010) Because advanced medical technologies and cares can mitigate PLWHA suffering and increase QoL. Thailand Ministry of Public Health provides free of charge antiretroviral therapy (ART) to PLWHA to improve QoL among Thai PLWHA. However, HIV/AIDS stigma and discrimination can severely compromise PLWHA's QoL by reducing access to health care adherence to therapy, and discourage the disclosure of HIV status (Zelaya et al., 2012).

PLWHAs have been faced with physical, psychological and well-being constrains due to societal norms (Basavaraj et al., 2010). According to Goffman (Goffman, 1963), PLWHA represent a social group that is considered to express a negative deviant behavior, and is likely unaccepted by society. Perceived stigma involving social rejection, social isolation, and financial instability (Choonhapran, Thanasilp, & thato, 1998; Fife & Wright, 2000) can force hopeless feelings and frustration among PLWHA (Holmes, Bix, Meritz, Turner, & Hutelmyer, 1997). On the other hand, obtaining social support, a positive feeling they are accepted as part of others' live can provide hope and feeling of social belonging to PLWHA. These two factors affected PLWHAs' QoL differently (Li, Lee, Thammawijaya, Jiraphongsa, & Rotheram-Borus, 2009).

In Lopburi province of Thailand, during September 1984 - November 2011, number of PLWHA was 3,567 cases and died 713 case.(Pansuwan & Jantaramanee, 2014) Lopburi province ranks the fifth in central regions in numbers of HIV case and is well recognized that the area of the religious-related foundation for PLWHA, namely Wat Phrabatnampu.

Understanding level of perceived stigma, social support and quality of life among PLWHA in this setting could provide insightful data that could be used to improve PLWHA's prevention and control plans. This study aimed to measure levels of perceived stigma, social support and quality of life among PLWHA and the associations among these selected factors.

Methods

Study design and participants

A cross-sectional study was conducted in Lopburi Province from 15 July 2018 to 15 January 2019. Six of eleven ARV clinics of the public hospitals in the area were randomly selected namely King Narai Hospital, Khok Samrong Hospital, Phatthana Nikhom Hospital, Thawung Hospital, Nong Muang Hospital and Khok Charoen Hospital. (Table 1) Sample size calculation was performed using a single proportion sample with a finite population. Inclusion criteria were PLWHA aged 18 to 60 years old, HIV diagnosed by a physician, residing in Lopburi Province, currently taking ART, and could communicate properly. The eligible PLWHA were purposively selected from the selected hospitals by probability proportional to size.

Table 1 Number of PLWHA in 6 ARV clinics and sample

Sampled ARV clinic	Total PLWHA (n)	Proportion (%)	Total PLWHA selected (n)
Kingnarai hospital	1,900	69.22	250
Khok Samrong hospital	330	12.02	44
Phatthana Nikhom Hospital	220	8.01	29
Thawung hospital	135	4.92	18
Nong Muang hospital	100	3.64	13
Khok Charoen hospital	60	2.19	8
Total	**2,745**	**100.00**	**362**

Research Questionnaire Interviews

Content validity of this study's instrument was assessed by three experts and reliability was conducted among 30 PLWHA. The structured questionnaire comprised four parts. First, general characteristics and clinical factors including gender, age, occupation, monthly income, marital status, educational level, disclosure status, current CD4 level and duration of illness. Second, perceived stigma developed by Fife BL. & Wright BR. (Fife & Wright, 2000) translated to Thai version (Uthis et al. 2018) involved four domains: social rejection, financial instability, internalized shame , and social isolation, totaling 24 items. Cronbach's alpha of the perceived stigma was 0.90. Third, social support consisted of four domains; emotional support involves the provision of empathy, love, trust, caring and respect that

PLWHA got from others; appraisal support involves the provision of information that useful for self-evaluation purpose; information support involves provision of suggestion; advice and information that a person can use in addressing problem which PLWHA got from others; and instrumental support involves the provision of tangible aid and services, totaled 14 items. Cronbach's alpha of the social support was 0.75. Fourth, WHOQOL-HIV BREF, totaled 31 items. (O'Connell, Skevington, & Saxena, 2003) comprising six domains: physical, psychological, level of independence, social relationships, environment and spirituality covering 29 specific facets an additional two items pertaining to global QoL and general health. Cronbach's alpha of the WHOQOL-HIV BREF was 0.80.

Data analysis

General characteristics, clinical factors, perceived stigma, social support and QoL were described by frequency, percentage, mean and standard deviation. Binary logistic regression was used to determine the relationship of general characteristics, clinical factors, perceived stigma and social support with a good level of QoL. The confidence interval at 95% and p-value at 0.05 level was considered statistically significant.

The 4-point Likert scale of perceived stigma ranges from strongly agree, to strongly disagree and was scored 1 to 4 with scores ranging from 22 to 88 points. Higher score reflected a higher perception of stigma. The 5-point Likert scale of social support ranges from never to always and was scored ranging from 1 to 5 with scores ranging from 14 to 70 points. The 5-point Likert scale of the WHOQOL-HIV BREF ranged from never to always and was scored 1 to 5. QoL scores ranged from 31 to 155 points. Our used 75 percentile cut of point, QoL above 75% was classified in a good level (score 115 - 155) and under 75 percentile was poor level (score < 115). The variables in this study has been reviewed forasmuch that can affect QoL, thus that can be confounder in this study. Multivariable model for control confounder effect, that set p-value not more than 0.3. The potential confounding factors in the model by entering method model.

Ethics consideration

The study was approved by the committee on Human Research Faculty of Public Health, Mahidol University (COA. No. MUPH 2018-098). The participants were explained regarding the protocol and asked to sign a voluntary consent to join in the research project.

Results

General characteristics

Of 415 PLWHA, 362 PLWHA consented to participate in the study. Among respondents, 50% were female, aged between 18 and 69 years (Mean 42.5; S.D. 10.57). More than 50% were Temporary worker (person with no permanent job, but who his paid on a daily basis for temporary work), with

monthly income ranging between 200 to 100,000 THB (Median 9,000 THB). Almost one half were married and 85% attended high school or lower. More than one half lived with a spouse or parents. (Table 1)

Percentage of QoL, perceived stigma and social support

Of 362 respondents, (85.1% reported possessing a good level of QoL (mean score 123.63, S.D. 15.14) and more than 80% reported having a good level of each QoL facet except social relationship and environmental facet reported (at 70.2% (mean score 16.46, S.D. 3.06) and 40.1% (mean score 25.01, S.D. 4.15), respectively. Almost two thirds of respondents (68.5%) perceived a low level of stigma varying between four domains, 59 to 84%. About 70.2% of respondents reported perceiving a high level of social support and 90% perceived a good level of each social support domain except emotional support (71.3%) and instrumental support (63.0%). (Table 2)

Table 1 Level of quality of life, general characteristics and clinical factors

Factors		n	%
Level of quality of life			
	Good	308	85.1
	Poor	54	14.9
Gender			
	Female	181	50.0
	Male	150	41.4
	Men who have sex with men	31	8.6
Age (year)			
	18 – 35	91	25.1
	36 – 55	234	64.6
	≥ 56	37	10.2
Median = 42; Mean = 42.5; S.D. = 10.57; Min = 18; Max = 69			
Occupation			
	Temporary worker	224	61.9
	Unemployed	53	14.6
	Merchant	36	9.9
	Agriculturist	28	7.7
	Government officer	15	4.1
	Other	6	1.7

Monthly income (THB)			
	No income	53	14.6
	< 15000	226	62.4
	≥ 15000	83	22.9
Median = 9,000 ; Mean 10,354.14 ; S.D. 11,399,95 ; Min = 200; Max = 100,000			
Marital status			
	Married	168	46.4
	Single	109	30.1
	Couple	54	14.9
	Widowed/Divorced	31	8.6
Education level			
	No formal education	10	2.8
	Primary school	184	50.8
	High school	119	32.9
	Associate degree	23	6.4
	Bachelor degree	18	5.0
	High than bachelor degree	6	1.7
	Other	2	0.6
Living companion			
	Spouse	102	28.2
	Parent	86	23.8
	Alone	57	15.7
	Spouse and Child	41	11.3
	Cousin	30	8.3
	Child	24	6.6
	Spouse and Parent	14	3.9
	Friend	8	2.2
Mode of transmission			
	Unknown	96	26.5
	Spouse	114	31.5
	Temporary couple	130	35.9
	Share syringes	16	4.4
	Vertical	6	1.7

Table 2 Scores of participants' perceived stigma, social support and QoL (n=362)

Domain	Mean (S.D.)	Min-Max
Overall Quality of Life	123.63(15.14)	66 - 145
Psychological health	17.23(2.85)	10 - 20
Physical health	21.93(3.17)	12 -25
Level of Independence	17.54(2.85)	5 – 20
Social relationships	16.46(3.06)	7 – 20
Environment	25.01(4.15)	10 - 30
Spirituality/Religion/ Personal beliefs (SRPB)	17.12(2.92)	6 - 20
Perceived Stigma		
Overall stigma	46.77 (13.20)	22 - 74
Social rejection	14.00(5.33)	8 - 29
Financial instability	5.93(3.27)	3 - 12
Internalized shame	14.11(4.28)	4 - 16
Social isolation	12.73(5.45)	7 - 28
Social support		
Overall social support	59.59(8.42)	38 - 70
Emotional support	16.16(2.98)	9 - 20
Appraisal support	8.14(1.17)	5 - 19
Information support	16.63(2.10)	9 - 15
Instrumental support	18.66 (4.69)	10 -25

The result showed that PLWHA who perceived greater stigma had poorer QoL 81% compared with others (OR 0.19; 95% CI, 0.12 - 0.30). Social rejection has been significantly linked to QoL, and those who perceived more social rejection had a lower level of QoL at 83% (OR 0.17; 95% CI, 0.09 – 0.31) on the other hand overall social support was significantly associated with QoL. PLWHA, who had a high level of overall social support tended to perceive having a good QoL (OR 2.56; 95% CI, 1.42 - 4.62). (Table 3)

Table 3 Crude and adjusted odds ratio (OR) of perceived stigma and social support with quality of life (n=362)

Stigma and Social support domains	OR	95% CI	*p*-value	ORadj	95% CI	*p-value*
Overall stigma	0.19	0.12 - 0.30	< 0.001			
Social rejection	0.17	0.09 – 0.31	< 0.001	0.84	0.76 - 0.92	< 0.001*
Financial instability	0.99	0.62 – 1.56	0.953	0.93	0.82 - 1.07	0.317
Internalized shame	1.04	0.64 – 1.70	0.866	0.99	0.88 - 1.13	0.969
Social isolation	0.63	0.39 – 1.03	0.062	0.93	0.85 - 1.02	0.121
Overall social support	2.56	1.42 - 4.62	0.002			
Emotional support	0.66	0.26 - 1.69	0.390	1.04	0.84 - 1.29	0.718
Appraisal support	2.73	0.62 - 12.03	0.184	1.89	1.31 - 2.70	0.001*
Information support	2.75	0.58 - 13.19	0.205	0.91	0.64 - 1.31	0.620
Instrumental support	1.76	0.74 - 4.19	0.201	1.07	0.95 - 1.21	0.252

*P-value < 0.05 and adjusted for gender, occupation, opportunistic infections, CD4, disclosure status.

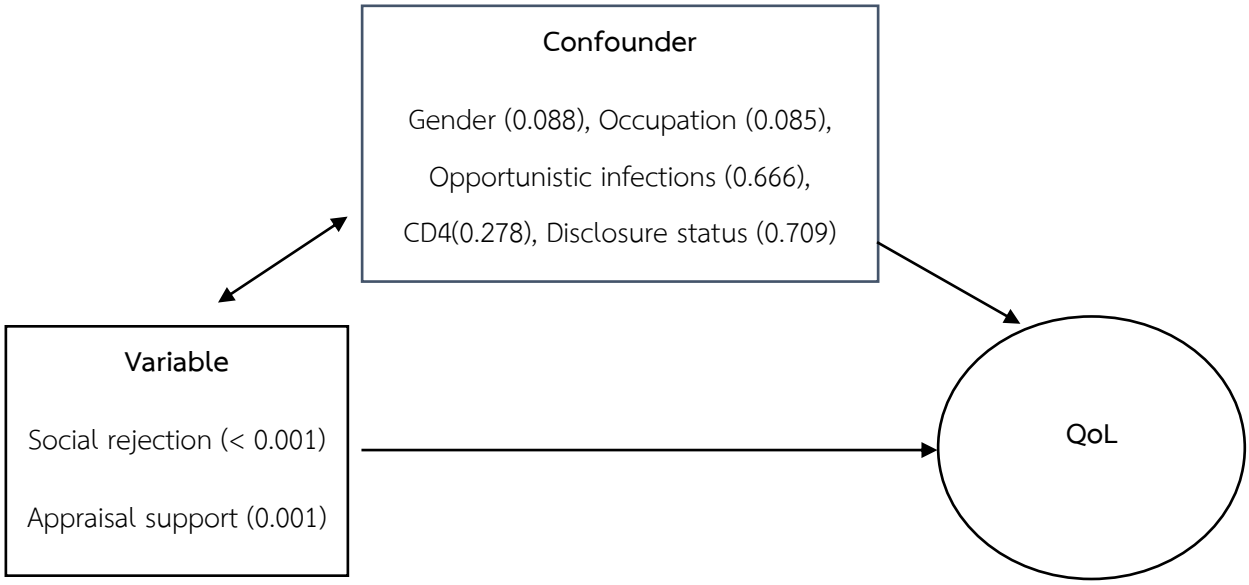

Fig. 1 Model confounder's selection after adjusted. (p-value)

All factors with p-value < 0.3 were further analyzed by multivariable model including sex, occupation, opportunistic infections, CD4, disclosure status, perceived stigma and social support. The entering method binary logistic regression revealed that appraisal support (ORadj = 1.89, 95%

CI = 1.31 - 2.70) was associated with good level of QoL. Otherwise social rejection was associated with poor level of QoL (ORadj = 0.84, 95% CI = 0.76 - 0.92). (Table 3).

Discussion

The study found that majority (85.1%) of PLWHA reported having a good level of QOL and a large percentage also reported having a good level of both physical health and psychological health were reported (80.9% and 92.8%). This study found the QoL levels of PLWHA in Lopburi Province were at a high level similar to the study in Taiwan (Hou et al., 2014). The result was in contrast to studies conducted in China (Zhu, Liu, & Qu, 2017), Ethiopia (Tesfaye et al., 2016), Finland (Nobre et al., 2017), Georgia (Karkashadze, Gates, Chkhartishvili, DeHovitz, & Tsertsvadze, 2017), Indonesia (Handayani, Ratnasari, Husna, Marni, & Susanto, 2019), Nigeria(Bello & Bello, 2013), and Vietnam (Tran et al., 2012), these all showing a moderate level in all facets but a low level in social relationships.

Even related studies in Thailand, (Khumsaen, Aoup-por, & Thammachak, 2012; Sakthong, Schommer, Gross, Prasithsirikul, & Sakulbumrungsil, 2009; Sakthong, Schommer, Gross, Sakulbumrungsil, & Prasithsirikul, 2007) found that PLWHA perceived a moderate level of QoL except in environment domain and social relationship domain (Siriporn et al., 2010). The high level of QoL in our study compared with other studies in Thailand, that may have been due to a long run of various activities and group support in Lopburi Province, such as Wat Phra Baht Nam Phu and Bann Gerda. These charities and others non-government organizations have been contributing to caring for and improving the well-being of PLWHA for several decades. The religious-charity foundation's activities may transform social perception about HIV/AIDs. In this area. Also, HIV treatment and care in Thailand is under the universal health coverage in which all PLWHA can access free-of-charge ART service which may lead to a better physical health domain among PLWHAs.

The study has showed significant association between high appraisal support with good QoL. (ORadj = 1.89, 95% CI = 1.31 - 2.70). These results are similar to the related study of QoL among patients with cancer (Trevino, Fasciano, Block, & Prigerson, 2013). Similar to studies Thailand, they showed significant correlation between social support and QoL(Rotheram-Borus et al., 2010). All results from a related study showed social support was significantly associated with high QoL among PLWHA (Charkhian et al., 2014; Garrido-Hernansaiz, Heylen, Bharat, Ramakrishna, & Ekstrand, 2016; Holtz, Sowell, VanBrackle, Velasquez, & Hernandez-Alonso, 2014; Mekuria, Sprangers, Prins, Yalew, & Nieuwkerk, 2015; Nyamathi et al., 2017; Xiao, Li, Qiao, Zhou, & Shen, 2017). From House's concepts of social support (House, 1981), appraisal support involves information for self-evaluation purposes, meaning that PLWHA who have someone to talk about problems, and provide knowledge, help PLWHA evaluation to be able to increase

the QoL level. Thus, ARV clinic staff should empower PLWHA and set up peer groups or counseling counters for PLWHA and family members to improve level of QoL.

The study showed that social rejection was negatively associated with good QoL. (ORadj = 0.84, 95% CI = 0.76 - 0.92). Similar to the related study, PLWHA were discriminated at work and in society generally had poor QoL (Greeff et al., 2008; Xu et al., 2017). PLWHA perceived that others showed less respect, felt awkward and avoided them and caused them to feel low and lack of self- esteem. (Bharat, 2011; Chandra, Deepthivarma, Jairam, & Thomas, 2003; Pila JM, 2019). Our results consistent with related studies in Brazil, Ethiopia, Mexico, and India showing that people with who were stigmatized, suffered, and felt prejudice had poor relationship with QoL (Charles et al., 2012; Garrido-Hernansaiz et al., 2016; Holtz et al., 2014; Nyamathi et al., 2017; Oliveira, Moura, Araújo, & Andrade, 2015; Subramanian, Gupte, Dorairaj, Periannan, & Mathai, 2009; Thomas et al., 2005).

In addition, the study results followed the stigma concept that perceived social rejection reflecting PLWHA's feeling of discrimination against them at work and society, perceived receiving less respect, avoiding them and appearing to feel awkward (Liamputtong, Kitisriworapan, & Deviance, 2012). Social rejection can reduce QoL because PLWHAs feel low and lack esteem leading to devaluing themselves.

Recommendation

This study emphasized that higher perceived stigma had a negative association with good quality of life, while increased social support had a positive association with good quality of life. To improve QoL, ARV clinic staff should enhance social support practices for PLWHA among health care service staff. Second, ARV clinic staff should empower PLWHA and set up peers group or counseling counters for PLWHA and family members. Third, ARV clinic staff should improve zero stigma and discrimination services. Next, future studies should be conducted in community-based setting to better understand PLWHA who lack accessibility to care and prospective cohort designed studies can be conducted to follow-up the change in QoL among PLWHA who have received or not received ART.

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