Attitudes and barriers towards HIV screening: A qualitative study of people living with HIV/AIDS (PLWHA) in Malaysia

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Abstract

Background: Understanding patients' perspective towards HIV screening in Malaysia is pivotal to explore challenges faced by these individuals. This would be beneficial for developing local plans to improve the health-seeking behaviours among population at risk of HIV/AIDS.

Methods: A qualitative research methodology was adopted to explore HIV/AIDS patients' views about disease screening. A semi-structured interview guide was used for in-depth patient interviews. All interviews were audio-recorded and were subjected to a standard content analysis framework for data analysis.

Results: Most patients were positive about screening and the value of knowing about their status early. However, fear of social stigma, discrimination, lack of support system and lack of public understanding were identified as major concerns affecting their willingness to be screened. They were concerned about mandatory screening being implemented without improvement in support system and public education.

Conclusions: Reluctance to seek HIV screening is an important factor contributing to transmission in developing countries. In the Malaysian context, efforts should be made to strengthen screening strategies especially in the most-at-risk populations to monitor the epidemic and target prevention strategies.

Practice implications: In a multicultural context, HIV preventive strategies must include disease awareness, including measure to tackle barriers towards screening.

Keywords

HIV/AIDS, disease screening, qualitative methods, patients' perspective, acceptance and barriers

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Introduction

According to the World Health Organization (WHO), while there is still no cure, most people living with HIV or at risk for HIV do not have access to prevention, care and treatment (Anon, 2013). However, HIV testing has helped millions of people learn their status, and options for long-term care and treatment can thus be offered for those testing positive (World Health Organization, 2014). This screening process is crucial in the crusade against HIV/AIDS as an

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early detection of HIV status for the people living with HIV and AIDS (PLWHA) and allows early initiation of treatment, hence greatly reducing HIV-related morbidity and mortality, transmission between mother and child, as well as between partners (World Health Organization, 2014). Knowledge of HIV-positive status is pivotal to any effective HIV prevention and care program, which has made access to HIV screening a public health imperative (Napierala Mavedzenge et al., 2013) in the fight against increasing epidemics, particularly among populations with highest risks of infection (Johnson et al., 2014).

HIV positive cases in Malaysia are still prevalent among the most-at-risk populations (MARPs) (Ministry of Health Malaysia, 2014). In Malaysia, HIV screening is provided for free in all government healthcare facilities via two different programs: voluntary and confidential HIV test (VCT) as well as Provider Initiated Testing and Counselling (PITC). The various strategies implemented for HIV screening include screening of all donated blood, blood products and organs, an opt-out antenatal screening, routine screening of inmates in drug rehabilitation centres and prisons, tuberculosis (TB)/sexually-transmitted infection (STI) cases, as well as premarital screening (Ministry of Health Malaysia, 2014). Although the country has made considerable progress in the battle against HIV/AIDS, increasing trends in cases has shifted from injecting drug users (IDUs) to sexual transmission (Barmania, 2013; Ministry of Health Malaysia, 2014), and an increase in the number of female cases has been observed in the recent years (Ministry of Health Malaysia, 2014). In fact, women have a higher tendency to engage in injection and sex risk behaviours as opposed to men; both receptive and distributive injection equipment sharing were more prevalent among female IDUs than male IDUs in Malaysia. Female IDUs are more likely to engage in risk behaviour probably because women may be more stigmatised by their drug use, which in turn may result in more risky behaviour (Mondal and Shitan, 2011).

Although HIV screening may prove beneficial in many ways, it is fundamental to gain insight into the patients' perspectives on screening to support its successful implementation. Similarly, gauging the patients' perspectives may also help in overcoming misconceptions about HIV screening. Thus, understanding the patients' outlook on HIV screening facilitates a more rational approach to HIV screening. In Malaysia, the MARPs for HIV transmission include IDUs, sex workers, men who have sex with men (MSM) and transgenders, with an estimated high prevalence (3–20%) of HIV infections among these groups (Choy, 2014; Ministry of Health Malaysia, 2011, 2014). Although efforts are being made in tailoring specific strategies towards risk behaviours among these groups, limited data are available to support such strategies in addressing the barriers towards HIV screening. The present study is therefore aimed at exploring HIV/AIDS patients' perspective towards screening, to identify their attitudes and barriers to the issue.

Methods

Design and setting

The study was carried out according to the principles expressed in the Helsinki Declaration. Approvals from the Medical Research & Ethics Committee (MREC) and Clinical Research Center (CRC), Ministry of Health Malaysia, were obtained prior to the conduction of the study. The study was also registered under the National Medical Research Registry (NMRR) database. The study was conducted at the largest referral centre for infectious diseases in the country, which was the chosen site for data collection. Since little is known about Malaysian HIV/AIDS patients' stance on HIV screening, a qualitative methodology was adopted to explore the issue.

The participants

Malaysian patients aged 18 years or older, diagnosed with HIV/AIDS attending outpatient clinics, were approached to participate in this study between January and May 2013. Participants were randomly approached based on the above criteria and were given explanation on the purpose of study, along with the study information sheets in Malay and English languages. Both written and verbal consents were obtained prior to data collection. A total of 15 patients were approached, however a saturation point was reached at the 13th interview and no new information was obtained from subsequent interviews.

Study tool

A semi-structured interview guide was used for the purpose of data collection. The interview guide was developed after extensive literature review, whereby a list of possible questions to assess the patients' perspective on HIV/AIDS and its screening were identified. Open-ended questions were created so that it can provide interviewees with maximum opportunity to express their views. The initial version of the draft questionnaire was discussed among the authors and was modified after a few rounds of discussion. In addition to checking whether the particular given set of questions were useful in the retrieval of objective information, a pre-testing of the interview guide was carried out by conducting pilot interviews with HIV/AIDS patients; however, these data were excluded from actual findings of the study. Finally, specific probes identified during pilot interviews were added to the interview guide.

Procedure and interview process

Interviews were conducted in the English language as majority of the participants were comfortable with the language; the Malay language was also used for patients who preferred this language. Each interview lasted for approximately 25–65 min. All interviews were audio-recorded and

the principal investigator attended all interviews with the research assistant to take field notes and facilitate the interview process. The interviews were mainly focused on study objectives and probing questions were also used where necessary to obtain a more thorough understanding of the issue involved. Each transcribed interview verbatim was then sent to the study participants for clarification and mutual agreement. Patients' demographics, together with relevant disease and treatment-related data, were also obtained prior to the interviews. All transcribed interviews were later subjected to thematic content analysis framework (Vaismoradi et al., 2013).

Results

A total of 13 patients (PT1–PT13) with a mean age of 34.4 years were interviewed; the majority (46.15%) were aged 18–30 years. Of the 13 participants, 12 were men, Malay (61.54%) and unmarried (84.62%). Table 1 provides detailed sociodemographic characteristics of the study participants.

Attitude towards HIV screening

Perceived effectiveness, barriers, cues for improving screening behaviour and perspective on mandatory screening emerged as main sub-themes among PLWHA.

Perceived effectiveness of HIV screening

Positive attitude towards screening. Most of the patients showed positive attitudes towards HIV screening. They agreed that HIV screening will help people acknowledge and understand their status which will also help increase the awareness among people with high-risk behaviours. However, most of them were slightly sceptical about the usefulness of such screening in preventing HIV epidemics, rather they believed that it can significantly impact their social life.

'From a strictly medical perspective, I suppose it would help, just like it screens people for leprosy or tuberculosis.' (PT1)

'... promoting screening is not preventing HIV for me, is ... getting know your HIV status, because that ... promoting screening is, is just ... an awareness to those who have high-risk behaviour.' (PT4)

'Because ... people know their status, then they can work to, they can protect themselves and they can protect other people if they know, their status.' (PT9)

'... You know, (health) is not about thinking of our population, but we also have to think about the patient, you know, the one who really involve in it. So it has benefit, and at the same time it has social impact as well.' (PT2)

Barriers to HIV/AIDS screening

Social stigma. A number of patients expressed their fears of the stigma associated with HIV screening. Most of them

Table 1. Sociodemographic characteristics of the study participants (n = 13).

Variables	n	%
Age (years) (mean, 34.4 years)		
18–30	6	46.15
31–40	4	30.77
41–50	2	15.38
>50	1	7.69
Gender		
Male	12	92.31
Female	1	7.69
Ethnicity		
Malay	8	61.54
Chinese	1	7.69
Indian	3	23.08
Others	1	7.69
Marital status		
Married	2	15.38
Unmarried	11	84.62
Education level		
Secondary education	5	38.46
Diploma	4	30.76
Graduate	3	23.08
Postgraduate	1	7.69
Occupation		
Unemployed	3	23.08
Self-employed	2	15.38
Private	7	53.85
Government	1	7.69
On HIV treatment		
Yes	10	76.92
No	3	23.08

considered social stigma as a result of HIV status and lack of social support systems as one of the most significant barriers as to why many people are afraid of HIV screening, and often refuse to opt for it.

'Well, will screening prevent HIV and AIDS? I don't see how. I think there has been a lot more fear. Because of the stigmas around HIV, that you say something like there's going to be a screening, people will just get really scared of you, people may not want to do that ... I'm a bit more worried about the fear that will generate.' (PT1)

'But you know you have to take it in ... the context of the stigma that HIV creates, and I'm just worried about my name being on the piece of paper.' (PT1)

'I'm worried about when it comes to screening, whether we have that kind of back-up system, whether we can deal with the stigma.' (PT1)

Fear of confidentiality. Patients raised their concerns on issues of privacy and confidentiality due to HIV screening and believed that their name will be documented as positive for HIV status, that the information may not necessarily remain confidential and others will soon be aware of their status. In their view, patients should not be forced for such screening against their will as this is unjustified to their basic human rights.

'... if, let's say, you think of doing screening openly, widely ... eventually it will come to a point where there's no more ... confidentiality, you know ... the information is somehow will be ... leak.' (PT2)

'Some people gonna ... protest because yeah they ... think this is kind of privacy, I mean people cannot force this is human right; I mean if they don't want you cannot force right? So, but this is good, this is what I can say.' (PT10)

Cues to action/ways to improve screening behaviour

Need of a support system. Participants suggested ways to improve HIV screening behaviour among populations at risk by providing a more robust support system which can aid the patient in dealing with issues once they are aware of their HIV status. Further, they suggested that educating people towards the benefits of HIV screening and at the same time empowering them will help in dealing with barriers to HIV screening. They also viewed that in the absence of strong social support systems and optimal education programs, negative attitudes will continue to challenge the success of any prevention program. They gave examples of cancer screening that they believe have similar barriers.

'I would also say that you only should go for HIV testing if you're very clear about the support systems that you have because of the stigma ... and because of the fear generated around it. Similarly, cancer as well. You should only go for cancer testing if you have a support system ... I'm worried about when it comes to screening, whether we have that kind of back-up systems, whether we can deal with the stigma?' (PT1)

Need of public education. *'I think education will help, I think just informing people ... we know that even if you have like say blood, if you have a sore on your penis, then it's an STD ... if you have unsafe sex then go and get tested. ... just empowering people to take charge of their health. I believe that would be better than general screening.'* (PT1)

Perspective on mandatory HIV screening

Benefits in preventing epidemics. Patients recorded their views towards the benefits of mandatory HIV screening, and although most of them agreed on its possible effectiveness, a few were of the opinion that mandatory screening

alone was not sufficient for preventing transmission. For some, they will continue their lifestyle in the same way even after acknowledging their status. This perhaps indicates a greater need of behavioural intervention to change attitudes of people living with high-risk behaviours.

'More people knowing their status would definitely help, you know. I think people should know than don't know ... So if screening can help in that sense, in creating awareness about their own health then I would agree.' (PT1)

'I think should be, because ... I think still have a lot of people don't know their status.' (PT9)

'I do think it can help, yes ... everyone ... I can say based on my experience among my friends, they don't do the screening test, and I saw ... they are very suffering.' (PT10)

'... because if we do lot of promotion, people still do the same way, their lifestyle is like that. So, for certain people maybe yes, for certain people maybe it will not affect.' (PT3)

Issues and concerns. Most participants raised their concerns about 'mandatory HIV screening'; they feel that the screening should be on a voluntary basis and that the authorities must take measures to deal with issues of social stigma and discrimination against HIV patients, should such mandatory screening be implemented in future.

'I still think screening should be voluntary. It should definitely not be hidden. Just screen everybody, take everyone's blood without telling them what they're taking the blood for. I think that's abusive.' (PT1)

'... but before that, the government have to do something to reduce the stigma and discrimination, make the society aware about the HIV, give the right information, so make the world ... better understand on HIV' (PT6)

Discussion

Our findings provided an insight on perceptions of HIV screening among Malaysian PLWHA. We noticed that although the participants understood and appreciated screening as an important tool towards prevention of HIV epidemics, they were still concerned about issues related to confidentiality, stigma and lack of social support. Hutchinson et al. also found that study participants generally supported routine testing, but were uneasy about the confidentiality of routine testing programs, whereby the men in the study group feared death and the emotional consequences of testing positive, while women on the other hand feared rejection and discrimination by society and at the workplace, respectively (Hutchinson et al., 2004). This confirms that even after two decades, there is still a fair amount of misinformation, stigma and misconceptions related to HIV testing; these factors should be taken into consideration when refining the HIV screening program, and issues of confidentiality and voluntary consent should therefore be considered (Hutchinson et al., 2004).

Numerous studies have been conducted evaluating HIV screening attitudes among various population groups including students, chronic diseases, etc.; however, limited data are available on perspectives of PLWHA. Many quantitative studies that have involved various other population groups have generally reported a positive attitude towards HIV screening (Brown et al., 2008; Dietz et al., 2008; Haukoos et al., 2010). However, qualitative studies provide a better insight into perceptions and attitudes, and can highlight misconceptions and barriers towards screening (Ahmadnezhad et al., 2013; Hutchinson et al., 2012; Musheke et al., 2013).

HIV screening is the first and paramount step in knowing disease status and it is essential for any prevention program (Sharma et al., 2015). Nevertheless, it is reported that HIV screening rates remained low among high-risk populations (Fogg and Mawn, 2010). Rothman et al. highlighted the social importance of Emergency Department (ED) screening, as it is directed at underprivileged and socially excluded groups (Rothman et al., 2003). Although the benefits of HIV screening may be many, screening is perceived differently among various populations. For example, older adults expressed the importance of the healthcare provider initiating and facilitating discussion about sexual health (Nusbaum et al., 2004). It is also noted that they may be more vulnerable to sexually transmitted diseases due to their lack of knowledge (Negin et al., 2014), hence reiterating the importance of communication with healthcare workers (Schensul et al., 2003).

There are limited data available on HIV screening among Malaysian PLWHA. However, a Malaysian study among cancer patients reported poor understanding and barriers towards cancer screening and had recommended more culturally specific educational strategies to improve screening acceptance (Farooqui et al., 2011). In the year 2001, the Malaysian Department of Religious Affairs (JAKIM [Jabatan Kemajuan Islam Malaysia]) introduced a gradual state-by-state mandatory premarital HIV screening program for prospective Muslim couples in the country to help in curbing epidemics (Barmania, 2013). Although Muslims are the majority population group, it is time to re-evaluate and extend this strategy to other minorities including at-risk groups in the country (Choy, 2014). While doing so, it is extremely important to gauge patients' perspectives in order to tackle the barriers and challenges faced by HIV-infected patients. In the light of the present study findings, social challenges including fear of stigma, lack of social support and poor public understanding about disease remained main barriers towards HIV screening in the country. Various factors contribute towards these discriminatory behaviours in the local context, and they can deter the effectiveness of any preventive strategies (Wong and Syuhada, 2011).

There is no doubt about the importance and effectiveness of HIV testing programs and access to such facilities are deemed as public health imperatives (Napierala Mavedzenge et al., 2013). While the world is moving

towards self-testing strategies for HIV (Johnson et al., 2014), it is vital for developing nations to explore and eliminate obstacles affecting the implementation of their programs. Malaysia, at present, is exploring the feasibility of integrating self-testing HIV test kits as part of prevention (Ministry of Health Malaysia, 2015). Knowledge of HIV status is key to implementing strategies directed at reducing the risk of transmission, including male circumcision, vaginal and rectal microbicides, oral pre-exposure prophylaxis (PrEP) and earlier/immediate antiretroviral therapy (ART) for prevention (Napierala Mavedzenge et al., 2013).

Implications to practice

In light of these findings, it is imperative that strategies must focus on not only increasing disease and screening awareness but also tackling other possible barriers towards screening among MARPs in the country. Given the fact that Malaysia is a multicultural country with people from various cultural and beliefs backgrounds (Hasanah et al., 2011; Ministry of Health Malaysia, 2014), strategies to curb HIV epidemics and to promote health-seeking behaviour must be contextualised to local settings. The conventional facility-based HIV-testing and Counselling (HTC) may not be enough; hence, community-based HTC modalities should be focused to optimise the objectives of HIV screening programs (Bärnighausen et al., 2012; Sharma et al., 2015; Suthar et al., 2013).

Study limitations

The study involved HIV/AIDS patients receiving care and treatment; however, their views may not reflect those patients yet to be screened or receiving any treatment. Data gathered at a hospital facility may also influenced their perspectives towards HIV screening. In addition, the study may not better reflect the views from female patients, since only one female patient agreed to participate; there may also be interviewer-related bias (knowing participants' disease status).

Conclusions

Encouraging people in high-risk groups to seek HIV screening is important to support early medical care of the patient, as well as to reduce transmission. Lack of understanding about the disease and fear of the social consequences associated with status disclosure are significant barriers for achieving a successful HIV screening programme.

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