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A qualitative insight of HIV/AIDS patients' perspective on disease and disclosure

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Abstract

Background Understanding patients' knowledge and belief towards disease could play a vital role from an outcome perspective of disease management and HIV/AIDS patients are not exception to that.

Methods Qualitative methodology was used to explore Malaysian HIV/AIDS patients' perspectives on disease and status disclosure. A semi structured interview guide was used to interview the patients and a saturation point was reached after the 13th interview. All interviews were audio-recorded and subjected to a standard content analysis framework.

Results Understandings and beliefs towards HIV/AIDS and Perspective on disease disclosures were two main themes derived from patients' data. Beliefs towards causes and cure emerged as sub-themes under disease understandings while reasons for disclosure and non-disclosure were resulted as main sub-themes under disease disclosure. Majority of patients apprehended HIV/AIDS and its causes to acceptable extent, there were elements of spirituality and lack of education involved with such understandings. Though beliefs existed that knowing status is better than being ignorant, fear of stigma and discrimination, social consequences and family emotions were found important elements linked to disease non-disclosure.

Conclusions The outcomes provided basic information about patients' perceptions towards disease and status disclosure among HIV/AIDS patients which can help in the designing and improvising existing strategies to enhance disease awareness and acceptance and will also serve as baseline data for future research further focusing on this subject.

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Introduction

Although globally the number of people newly infected with HIV/AIDS is declining, national epidemics continue to expand in many parts of the world.[1] Even though much has been achieved in terms of treatment outcomes due to the global solidarity in the AIDS response during the past decade,[2] the chronicity of HIV/AIDS still poses challenges to the patients' life.[3] Therefore, until the day HIV/AIDS cure will be possible, delay in HIV/AIDS-related mortality and related complications with improve quality of life (QoL) will remain as main outcomes of the treatment and to achieve this, equal and active participation of patient in the whole process of treatment is imperative. This accentuates on assessment of patients' perspective and understanding towards disease and its management.[4] Patients with chronic diseases might be expected to encounter increasingly complex barriers given the need for long-term care and treatment, and it is clear that these barriers can have very serious consequences in terms of delayed treatment, inappropriate healthcare-seeking behaviours, poor adherence to treatment regimens or even a decision to forego treatment.[5]

HIV/AIDS is widely recognized as a chronic illness within HIV care, but is often excluded from chronic disease lists outside the field. Patient-related principle elements of chronic disease management such as understanding illness and wellness, health promoting behaviours, preventing transmission are some of the essential elements in the integrated framework of chronic HIV care.[6] Therefore, exploring such elements can help improvising existing HIV/AIDS treatment program by incorporating patients' perspectives into it as such perceptions influences their health-seeking behaviour and can complicate their treatment outcomes.[5] This in turn can help in optimizing patient care as well as dealing issues of non-compliance, delay in treatment, screening refusal etc.

Even though the regional prevalence of HIV infection is nearly 25 times higher in sub-Saharan Africa than in Asia, almost 5 million people are living with HIV in South, South-East and East Asia combined.[2] Many factors contribute to this high prevalence, from low levels testing and linkage to care and prevention, to poor retention in care and adherence to antiretroviral treatment.[7] Malaysia is a country with extensive cultural and ethnic diversities with range of spiritual traditions and believes,[8–10] and the epidemic in this country is still concentrated within most-at-risk populations (MARPS) especially among IDU (Injecting Drug Users), sex workers and transgender population with a decline in annually reported new cases.[11] Currently Malaysian HIV/AIDS care strategies are focused on reduction in transmission, improvement in quality of care, alleviation of socio-economic and human impact among PLWHA (People living with HIV and AIDS), reduction in stigma and discrimination with improvement in disease awareness among general population.[10] Therefore, a strong reason for the need of such explorations is the fact that studies have found deficits in the spectrum of engagement in HIV care including late HIV diagnosis, suboptimal linkage to and retention in HIV care, insufficient use of antiretroviral therapy, and suboptimal adherence to therapy, which pose significant barriers to achieving optimal treatment outcomes.[12] This study therefore aimed to explore disease perspectives of Malaysian patients with HIV/AIDS, which to the best of our understandings were never investigated before.

Methods

Qualitative methodology

The use of qualitative methods is becoming more common in medical research in general and HIV/AIDS in particular.[13–15] Indeed, some have suggested that qualitative research is pivotal to our understanding of the socio-behavioural aspects of HIV disease.[16] Such studies in different parts of the world have revealed poor patient understanding and beliefs towards HIV/AIDS and its transmission[17–19] as well as spirituality linked to such believes;[20] however, only limited data are available as many of them focuses particular aspects in HIV care, contextualized to particular setting. Studies have also found fear of stigma resulting in refusal for HIV testing[21] and reasons for non-disclosure.[22,23]

Design and setting

The study was conducted according to the principles expressed in Helsinki Declaration, and was approved by the Medical Research & Ethics Committee (MREC) and Clinical Research center (CRC), Ministry of Health Malaysia. The study was also registered with National Medical Research Registry (NMRR) database. Little has been known about Malaysian perceptions of patients' with HIV/AIDS on subject matter; therefore, qualitative research was adopted to explore the issue. The study was conducted at Hospital Sungai Buloh, the largest referral centre for infectious diseases in the country. All interviews were conducted in closed counselling room especially arranged for the study.

The participants

Participants were selected from the outpatient infectious disease clinics between January and May 2013 with the help of convenience sampling method. Malaysian patients, 18 years of age or older, diagnosed with HIV/AIDS attending outpatient infectious disease clinics at Hospital Sungai Buloh were approached personally by principal investigator to participate in this study. Consulting medical doctors also helped in briefly informing the patients about the objective of the study while patients were having their appointments; however, participation was entirely on voluntarily basis therefore no financial or other forms of incentives were given upon study participation. Study information sheets in Malay and English languages were provided, and patients were also given verbal information on the research. 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 13th interview and no new information was obtained from the 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, where list of possible questions to assess the patients' perspective on HIV/AIDS and status disclosure were identified. Open-ended questions were created so that it can provide interviewees with a maximum opportunity to express their views. The initial version of draft interview guide was discussed among the authors (pharmacists and medical doctor) and was modified after a few rounds of discussion. Later this modified version of interview guide was subjected to review by medically qualified professionals, having experience in qualitative research. In addition to check whether 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 patients with HIV/AIDS. Finally, specific probes identified during pilot interviews were added to the interview guide. However, these findings of pre-testing interviews were excluded from data presented.

The interviewers

Interviews were conducted by principal investigator (Pharmacist/Lecturer) in the English language as majority of participants were comfortable with it; however, Malay language (national language of Malaysia) was also used for patients who preferred to communicate in it, for which a research assistant (Final year pharmacy student) was appointed to help. The research assistant was briefed about the study objectives, scope and procedure and had attended (shadowed) interview sessions with principal investigator prior to the conduction of any interviews.

Interview process and procedure

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 get a more thorough understanding of the issue involved. Each transcribed interview verbatim was then sent to the study participants for their approval. Patients' demographics along with relevant disease and treatment-related data were also obtained prior to interviews.

The Interviews in Malay language were transcribed and translated into English by the research assistant, while the principal investigator transcribed and coded all interviews, and related themes were developed. All transcribed interviews were later subjected to thematic content analysis, and the transcripts were analysed for relevant content to identify the emerging categories.[24] For validation purpose, all analyses were reviewed by a medical doctor and an experienced pharmacy practice lecturer.

Results

A total of thirteen patients (PT1–PT13) with a mean age of 34.4 years were interviewed for data generation. Majority (61.54%) of the patients were Malay, male (92.31%), unmarried (84.62%) and from age group 18–30 years (46.15%). Almost all the patients had at least completed secondary education with one patient having postgraduate education. Most (53.85%) of the participants were working in private sector while only 23.08% were unemployed. Of these thirteen patients with HIV/AIDS, 10 (76.92%) patients were receiving antiretroviral treatment. Patients' detailed demographic characteristics are provided below in Table 1.

During the analysis, important themes were discovered in relation to patients' understanding towards HIV/AIDS and status disclosure, which elucidate their stance on subject matter. These include understanding and belief towards HIV/AIDS and perspective towards disease disclosure.

Understanding and belief towards HIV/AIDS

When patients were asked about their understanding and belief towards HIV/AIDS, following sub themes emerged.

Belief towards the causes of HIV/AIDS

Virus causes weaken immune system. Majority of the patients were aware that HIV is caused by a virus and it can leads to a weakened immune status, that is AIDS. Another important aspect of patients' understanding was their understanding towards the most common routes of HIV transmission, also the belief that both male and female carry equal risk to acquire this disease. Patients' generally regarded HIV/AIDS as dangerous disease which once acquired can lead to many diseases,

Table 1 Socio-demographics of the study participants (*N* = 13)

	Age (years)	Gender	Ethnicity	Marital status	Education level	Employment	On ARTs
1	50	Male	Indian	Never married	Graduation	Self employed	No
2	27	Male	Malay	Married	Graduation	Government	No
3	24	Male	Malay	Never married	Secondary	Unemployed	No
4	43	Male	Malay	Never married	Diploma	Unemployed	Yes
5	29	Male	Others	Never married	Secondary	Private	Yes
6	34	Female	Indian	Never married	Diploma	Private	Yes
7	39	Male	Malay	Never married	Secondary	Private	Yes
8	29	Male	Malay	Never married	Graduation	Unemployed	Yes
9	28	Male	Chinese	Never married	Diploma	Private	Yes
10	32	Male	Malay	Never married	Graduation	Self Employed	Yes
11	32	Male	Malay	Never married	Post Grad	Private	Yes
12	54	Male	Indian	Married	Secondary	Private	Yes
13	26	Male	Malay	Never married	Diploma	Private	Yes

which may indicate the fear of HIV/AIDS that they were living with.

> ... HIV is a virus that leads to AIDS. ... AIDS is a deficiency syndrome it affects the immunity of the body. Well it's a virus and we're not really sure where the virus is come from, well it definitely gets passed on through sex, through drug user among, from mother to child, through the milk. (PT1)

> It's a kind of virus infection which causes deficiency in immune system of a person. (PT2)

> If you're, if you're having one monogamous relationship, the risk for you to get this is much less, than again if you're having, having, how to say, multi-partner, there might be a risk for you to get the disease is much higher... (PT5)

> it's very dangerous, and because of your immune system going to be low, weak and easy for you to get many diseases, and be infected with any viruses. (PT10)

> The virus is not discriminating anyone, if female and male... (PT6)

Spiritual attributes (divine punishment). A handful number of patients linked HIV/AIDS and its cause to a form of divine punishment or as a curse due to human sins or unacceptable deeds of morality, as explained by their faiths. In addition, they were also of an opinion that disbelievers or people who do not follow religious way of life are more susceptible to acquire this disease; hence, there is a close link between HIV/AIDS and religious norms, adhering to these would help one protecting him from this. However, it was also found that some patient disregarded HIV as a divine punishment rather a disease that requires a better understanding from every one.

> I come from a very strong catholic family, so I think people do think to a certain extent that if you're homosexual, and you know, God will give you HIV as a punishment for being homosexual... (PT1)

> Yes for me yes, it is related to lifestyle. Is a, me as a Muslim, when you are not taking care of yourself, you can get... About your sex life, about the forbidden things... (PT4)

> If you have a strong religious... maybe you are protected, you are protected... if we have HIV lah, compared to others like who are not strong with religious maybe (PT11)

However, a few did not believe having any links between HIV/AIDS and spirituality.

> HIV is a disease, is not the punishment from the God... So, is, the, the virus is not discriminating; everyone can get HIV. (PT6)

Lack of awareness leads to HIV. Most of the study participants generally agreed that 'lack of HIV awareness' among general population and teenagers in particular is a major contributing factor to growing HIV epidemics. They were also of view that they could have prevented themselves from HIV, provided they were given right information at right time. Patients also viewed lack of education from parents or elders in family, on sexual aspects of life and teenage issues directly linked to increase in risk of getting HIV. A few of them believed that cultural norms are important barriers, why such educations are not provided to young ones.

> I haven't seen my mother or my father, or my relatives talking about sex, you know. They were very... I don't know is it shy, is it respect, not really sure. But if they give me a right information on the right time, maybe in... secondary school- during that time... maybe I have a knowledge, you see. (PT6)

> This is very dangerous disease, what you call, spread among teenagers I can say that, and a lot of people need to know about HIV and how, and you still have a chance actually, which is... with a proper medication (PT10)

Life style as a cause of HIV. Interestingly, a number of patients linked life style as a risk of acquiring HIV/AIDS; when they quoted that being involved in bad habits like drug addiction or having multiple sex partners or mingling people with other bad habits can increase risk of getting HIV/AIDS. In other words, prevention from these and living within good environments will eventually decrease risk being infected with this disease.

> If we don't get addicted to drugs, surely we wouldn't be drawn to the disease. Our risks to get the disease is not high... and it's the same if we do not do random sex, it means that our risk of getting HIV is very low (PT7)

> ... for example your surroundings, your environment, what type of people you are mingle around... if you are mingle around with positive people, with good and have a positive values... (PT11)

Belief towards the cure of the disease

Differences on patients' understandings towards cure of HIV/AIDS were noted; when a few viewed it is curable/treatable or otherwise. Interestingly another important aspect of disease understanding was highlighted when few patients claimed that their understating regarding HIV and its cure was different before they got infected which highlighted lack of general public awareness about the disease which could also be accountable for growing epidemics.

> Before I got infected, I have this idea about HIV where, ok HIV is just a disease and disease is a disease. It probably sooner or later will cure... (PT2)

> I think HIV and AIDS is a two different things; HIV is something like we can still do, I mean, we can still, you know, manage to treat, ok. We can do the treatment, But AIDS I think, is hard to do the treatment. (PT3)

Participants regarded AIDS as the final stage in HIV disease process that leads to death. They considered AIDS similar to cancer and other non-curable diseases for which hopes were high that 1 day a cure can be found. Interestingly some patients highlighted an important aspect where some people claim that HIV/AIDS is curable and they have solutions for it, such misleading information also highlighted cultural beliefs towards diseases and cure.

> AIDS is similar like the critical process of HIV which is the last part ...I mean it is hard to be made better, is considered final part of life (PT11)

> AIDS still uncurable, AIDS is like cancer, like other disease that will make people die. (PT9)

Overall patients' had acceptable conceptions towards HIV/AIDS and its causes while accepting it as a disease that they have to live with for the whole life. To them it is a life changing disease therefore having a positive mindset will help dealing issues with HIV/AIDS.

Perspective on disease disclosure

As expected almost all patients were of opinion that they should keep their disease status to themselves. Lack of disease understanding among general public, deficiencies of social support system, fear of social consequences and family emotions were found main reasons of non-disclosure. Most of them feel that disclosure generates stigma although a few thought that family should be the one, if it is ever to be disclosed.

Reasons for non-disclosure

Family emotions. Most of the HIV patients were keen to keep their status to themselves or not to be revealed to their family, friends etc. Majority of them ranked family emotions as one of the most important reasons for non-disclosure and believed that such disclosure will only result in hurting family emotions, while they were also afraid that this may also revealed them their high-risk behaviours, for example homosexuality, drug abuse etc.

> It would be a bit difficult telling them (family) I'm positive. I think I've, I've no intentions of telling them... I was joking about it the other day and told the doctor that it will be easier to tell them I have cancer, or tuberculosis or if I was in a car accident and I lost a leg, that would have been easy. But I think there is a certain stigma around HIV that would be really difficult

> for me to tell my family, although they are very, very supportive. (PT1)

> So far just hospital and some other HIV patient know my status. And my family and err my, my colleague they don't know my status, because at this moment I still scare to let people now I'm HIV (PT9)

Lack of community awareness. Lack of general awareness regarding HIV/AIDS was also highlighted as an important contributing factor to non-disclosing behaviour as most of the patients were afraid that this lack of disease understanding could create greater issues of stigma and social discriminations once their status is revealed.

> Not much, I mean, I never tell my family. I think they won't understand... Just between good friends, just friends... Because I think they lack of knowledge about HIV, so when I tell them that I'm diagnosed, so I don't think they want to accept it (PT3)

> Because still have a lot of people don't know what is a HIV and AIDS. I, I scared err, I mean when they know I'm have HIV, I think they will scare. But for family, because hmm my parents don't know I'm homosexual and then I don't want to them, worry about that; so I decided not to tell them. (PT9)

Fear of losing job. A few participants also feared that status disclosure could result in losing their jobs, which in turn can make their life more miserable.

> People would want my job, and they might use this against me, or if I'm sick and they'll say I can't do my job very well, etc. But because I run my own business, it's not so bad... (PT1)

> Some of the employer put in the application form you have HIV? that one is stigma for us, in order for us to apply for the job, or the positions. Then we need to hide something, some information... I did, and I need to hide the information (PT11)

While some had fear of losing job a few had also shared the consequences of disclosure in form of lost job and employment, highlighting one of the most terrible social difficulties resulted with status disclosure.

> I was sacked from my job because I was on leave; I was in the ward for more than a month, 2 months... (PT13)

Fear of stigma and discrimination. One of the most important reasons for non-disclosures highlighted by almost all participants was fear of being stigmatized and discriminated upon status disclosure. They believed that peoples' behaviour is not going to be the same once they knew our status and have shared their experiences when they were marginalized both by public and authorities. They unanimously asked public for an equal treatment, similar to those without HIV/AIDS.

> This is very subjective... once they know your status, even though they don't said it, you will know it, you will understand the service, the way of speaking, the way of relationships, will be different... It will never be the same. (PT2)

> ... As human being when someone call you, 'Hey HIV guys, come here'... (PT4)

> No, no for me I'm HIV, then I'm HIV. So don't treat me in special. I'm a like others, you know, treat me as a human, that's all. I don't want as...any special...what... treated, I don't want that. (PT6)

> The discrimination issues I have received, I am speaking from experience... discrimination and stigma issues when I was in police captivity lah Ok, usually when we are in police captivity and the police know that we are HIV positive, they, first of all they wouldn't look at us decently... (PT7)

Reasons for disclosure

Positive support from friends and family. Some of the participants were in favour of sharing their status for which they have reasons and had shared their experiences as well. For those who shared their HIV status although the initial responses were not good, however, lately they found support by family and friends. Most of them regarded family and close friends as the only group of individuals with whom they were comfortable disclosing disease status.

> No, they (family) were quite shocked about it, but after I explained to them about, what is HIV… there is medications on it, and they, they understand. (PT5)

> My workplace, they really understand. I think because I am a manager, so no one can be discriminate me, except me, I am going to discriminate them. (PT6)

> Family is the only, based on my experience, family, my family is supportive lah, compared to my friends. I, I will not tell my friend, about this disease, because they will spread out the stories and everything; you know the Malay culture and whatsoever, their mouth can be saying bad, hah. (PT11)

Discussion

To the best of our knowledge this will be the first ever published qualitative study in the Malaysian context exploring patients' with HIV/AIDS believes and understanding which will help in better understanding patients' point of view and clarify their belief and perceptions, through a number of important themes identified. Living with HIV/AIDS poses dual challenges to the affected patients: both from disease as well as a continuous struggle in dealing challenges faced in day to day life. In the history of modern medicine, there has not been any other illness that is so entwined with moral, religiosity, social and existential values as HIV and AIDS.[9]

Our study revealed that Malaysian patients with HIV/AIDS had better understandings towards HIV/AIDS, its cause and transmission, where patients knew that it is caused by a virus mainly transmitted via sexual relationship, illicit injectable drug use and from infected mother to child. Hutchinson *et al.* in their study also found quiet similar basic understanding towards HIV and AIDS;[21] however, a study in France has shown patients considered sexual contacts as the only route of HIV transmission while patients' beliefs and perceptions regarding HIV/AIDS, the fear to be screened and difficulties to talk about sexuality were found as important barriers towards HIV screening.[19] Interestingly, study participants related HIV/AIDS to other non-curable diseases particularly 'cancers' and believed that HIV is curable but not AIDS. Another important aspect of their understanding was linking HIV/AIDS as a form of divine punishment, where patients' believe that careless and sinful lifestyle is the reason why people get this disease. This signifies the religiosity and spirituality linked to HIV/AIDS which was found in various cultures and believes and explored by a number of studies around the world.[19,20,25] Malaysia is a multiethnic and multicultural society where people live with various religious backgrounds; however, Muslims are the majority in this country. In the perception of some Muslim locals, PLWHA are considered to be living the punishment of their sinful activities like drug misuse and prostitution. Being infected with HIV is possibly, and probably, perceived as having weakness in character and being sinful.[9] Islamic teachings and values portrays sex outside of marriage as sinful, often believed to contribute to HIV transmission among those reject safe-sex practices.[26] Hence, religious leaders could play an important role in controlling disease epidemics,[26,27] in view of which in the year 2001. The Malaysian department of religious affairs, JAKIM (Jabatan Kemajuan Islam Malaysia) had introduced a gradual state by state mandatory premarital HIV screening program for prospective Muslim couples in the country to help in curbing growing epidemics.[8] Similarly, a French study also revealed that people believed that religion (Catholicism) was supposed to protect patients from high-risk relations,[19] this trend is further confirmed in a South African study which found various strong aspects of spirituality among PLWHA and implicated that such believes should always be contextualized to HIV/AIDS care by health-care professionals.[20]

As expected most of the participants believed lack of HIV/AIDS-related education and awareness in the society is the major cause of HIV epidemics. They perceived if they would have been educated on the issues related to various aspects of attitude and behaviours leading to HIV, the situation could have been different. Most of these patients regarded teenage as the most vulnerable to get involved with risky behaviours like intravenous drug use etc. Of course, there is no doubt about the need of education-based interventions especially for teenagers to minimize the risky HIV behaviours; however, the effectiveness of such interventions and programs greatly depends on how well cultural, religious, political, individual, societal, legal and resources-based barriers are addressed in any contextualized setting.[28] Although there are clear evidences that education can avert HIV through the application of effective school-based interventions and also mitigate the impact of the pandemic, there are several challenges to be overcome.[29]

Disease status disclosure was found as another important aspect among people living with HIV/AIDS (PLWHA) in Malaysia, where they linked many reasons with non-disclosure including, lack of disease understanding among general public, deficiencies of social support system, fear of stigma and social consequences, including respecting family emotions. This non-disclosure could be a contributing element in growing epidemics in the country as it was quoted in a Malaysian study that increasing number of HIV infections in females may indicate unsafe sex or failure of infected husbands to disclose their HIV status to their spouses.[9] The relationship between ART and status disclosure to partner (s), family and community is also poorly understood, with the majority of evidence coming from high income settings;[30] however, data from some of the developing countries suggested a distinctive pattern of disclosure that relies on third parties and intermediaries, especially religious leaders, as instruments of disclosure.[23] Fear of discrimination can be further defined as fear of social discrimination leading to social isolation and lack of support and fear of socio-economic discrimination which may lead to problems with jobs, housing, insurance and other practical socio-economic considerations.[31] Socio-economic factors could also be playing an important role in non-disclosing attitude among Malaysian PLWHA, as younger peoples are known to have more fears of job-related consequences, when compared to older HIV patients.[32]

The psychosocial challenges faced by PLWHA range from being exposed to stigma and discrimination to dealing with the anger and fear of living with a serious health problem.[33] PLWHA face stigma in part because infection with HIV is associated with moral failures and a breach of social norms and taboos,[34] this may had some influence on PLWHA, and they may have carried on with their lives in denial.[9] Stigma has been identified as one of the most poorly understood aspects of the HIV epidemic,[35] a South African study has suggested that stigma experiences were intertwined with other daily conflicts and together created tensions, particularly in gender relations, which interfered with attempts to regain normality.[36] Therefore, there is a strong need to understand stigma and discrimination-related issues and intensify stigma reduction with in local context because eventually the disclosure and linkage to care experience is crucial in forming patient attitudes towards HIV and HIV care.[37]

Study strengths

One of the strengths of this study is the qualitative nature as well as the first of its type in the country. Also, the interviewers involved were having no direct connections to the particular care facility; hence, we believe it could had minimal influence on participants views; however, knowing this patients may not be explicit in explaining their perspectives although they might viewed this as an opportunity to share their concerns and views.

Limitations

Interviews were carried out in a hospital setting when the patients' were there to receive treatment; this may perhaps influenced their belief and attitudes. In addition, the study sample consisted of patients already receiving care from the hospital; therefore, it may not reflect opinions of those who opt not to receive any treatment. Similarly, due to its qualitative nature it may not be reflective of all patients with HIV/AIDS in the country.

Conclusions

Given the unique nature of illness, HIV/AIDS care requires greater involvement of patients into their treatment plans and strategies, for which understanding patients' perspective is imperative. Patients' believes and understanding towards disease, and issues faced in daily life definitely influence their decisions on treatment compliance and adherence which in turns affects the usefulness of HIV control program. More cultural specific educational programs for both patients and public can help in improvising their understanding towards disease which may also benefit in minimizing stigma and discrimination issues and at the same time improve health-seeking behaviour among PLWHA.

Implications to practice and future directions

Patients' understanding is a key factor in engaging them into any HIV care program because disengaged individuals continue to contribute to the ongoing transmission of infection; therefore, engagement of HIV-infected individuals in care will be critical for individual health and the prevention of HIV transmission to others.[38] More qualitative studies are needed alongside quantitative findings in cultural and belief context to help better understand and manage HIV/AIDS globally. Some practical implications of our findings could include community-based interventions to reduce stigma and discriminations, strategies to overcome challenges and barriers to disclosure in order to promote health-seeking behaviour while strengthening social support for PLWHA. In addition, quantitative findings based on present study results as well as future researches by engaging HIV-infected patients not receiving any care and treatment would be helpful in better understanding the scope of the issues involved.

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