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Facilitators and Barriers Affecting Adherence Among People Living With HIV/AIDS: A Qualitative Perspective

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Abstract

Background: It is widely accepted that for HIV-positive persons on highly active antiretroviral treatment, high levels of adherence to treatment regimens are essential for promoting viral suppression and preventing drug resistance. **Objectives:** This qualitative study examines factors affecting the adherence to HIV/AIDS treatment among patients with HIV/AIDS at a local hospital in Malaysia. **Methods:** The data from purposefully selected patients were collected by in-depth interviews using a pretested interview guide. Saturation was reached at the 13th interview. All interviews were audio-taped and transcribed verbatim for analysis using thematic content analysis. **Results:** Fear and stigma of perceived negative image of HIV diagnosis, lack of disease understating, poor support from the community, and perceived severity or the treatment side effects were among the reasons of nonadherence. Appropriate education and motivation from the doctors and reduction in pill burden were suggested to improve adherence. **Conclusion:** Educational interventions, self-management, and peer and community supports were among the factors suggested to improve adherence. This necessitates uncovering efficient ways to boost doctor–patient communication and recognizing the role of support group for the social and psychological well-being of the patients.

Keywords
HIV/AIDS, treatment adherence, qualitative method, support group

Introduction

The unprecedented efforts in the fields of biology, pharmacology, and clinical care have contributed to progressively turn HIV infection from an inevitably fatal condition into a chronic manageable disease (1). Regardless of these unquestioned successes, the problem is far from being resolved: Even in countries with full access to antiretroviral treatment, life expectancy of people under highly active antiretroviral treatment (HAART) remains lower with respect to that of uninfected people (2). Although there is a global decline in the number of people newly infected with HIV/AIDS, many nations are still fronting challenges with expending epidemics; hence, despite much of the news on HIV/AIDS is encouraging in the present era, challenges sill remain (3). Numerous factors contribute to this high prevalence, from low level testing and linkage to care and prevention to poor retention in care and adherence to antiretroviral treatment (4).

It is widely accepted that for HIV-positive persons on HAART, high levels of adherence to treatment regimens are essential for promoting viral suppression and preventing drug resistance (5). Studies have also reported an increased risk of mortality among nonadherent patients with HIV (6). Likewise, since complete cure for HIV infection is not yet possible, treated people have to

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maintain lifelong adherence and facing the risk of delayed drug toxic effects (1). Many barriers, including mental health, substance abuse, belief and understanding toward HIV/AIDS treatment, treatment complexities, side effects, and lack of social support, were found resulting in poor patient adherence (7–12). Those who believe in the necessity and benefit of the medication are more likely to follow the treatment properly; thus, the quantity and quality of information have the potential to influence the ability of individuals to judge and participate in decisions concerning their treatment (13). Uptake of HAART is also found to be associated with perceptions of personal necessity for treatment and concerns about potential adverse effects, resulting in significant decline in adherence over time (14).

Quality health-care outcomes of any given program depend upon patients' adherence, while nonadherence can be a pervasive threat to health and overall well-being (15). Similarly, deficits in the spectrum of engagement in HIV care include late diagnosis, suboptimal linkage to and retention in HIV care, insufficient use of antiretroviral therapy (ART), and suboptimal adherence to therapy, posturing significant barriers in achieving optimal treatment outcomes (16). Therefore, it would be pointless simply changing the medications without addressing the adherence barriers (17,18).

Malaysia has gained substantial success both in the treatment and prevention of the disease since first cases were diagnosed in 1986. Although the result of the continuous efforts has been seen in terms of overall decline in the new infection, a shift in the pattern of disease spread from male to female (male/female ratio declining from 9.6 in 2000 to 5.5 in 2015) is also evident. And while prevalence among intravenous drug users is falling, sexual transmission, that is, female sex workers, transgender people, and men who have sex with men, continues to threat efforts toward preventive strategies (19).

Although several studies are published on the subject in various parts of the world, not many have utilized a qualitative approach; in addition, to the best of our knowledge, there aren't any published studies assessing the adherence among people living with HIV/AIDS (PLWHA) in the local context. The qualitative published works in other parts of the world have applicability to the local context, as qualitative findings are meant for in-depth understanding of issues and phenomenon rather than generalizability as in the case of quantitative studies. Qualitative studies could make important contribution, particularly when the research approaches deal with the respondents' own perspective since such methods are essential given the complexity of adherence (20); a qualitative methodology was therefore adopted to explore this issue as it can enable researchers to explore meanings, examine practices, identify barriers, and discover the reasons for the success or failure of interventions (21).

Methods

Study Setting

The study was conducted in the infectious disease ward of Hospital Sungai Buloh, the largest referral center for infectious diseases in the country. This is a fully equipped, tertiary care hospital with all medical and surgical specialties, serving a large number of patients in the country.

The Participants

For the present study, participants were selected from the outpatient infectious disease clinics between January and May 2013. Malaysian patients 18 years of age or older diagnosed with HIV/AIDS attending outpatient clinics at Hospital Sungai Buloh were approached for participation. The purposeful sampling technique was employed to look for information-rich cases. Based on the above criteria, participants were selected irrespective of their race or ethnicity and were identified through the hospital database and patient records in the wards; however, all personal information was kept strictly confidential. Study participants were briefed about the study objectives via a patient information sheets in Malay (national language) and English languages. Each participant was also briefed about the study objectives and interview process before starting the interviews, by the principal investigator, while both written and verbal consents were obtained prior to data collection. A total of 15 patients were approached for interviews; however, a saturation point was reached at the 13th interview and no new information was obtained from subsequent interviews, fulfilling the required sample size for phenomenological approaches (21).

Study Tool

After an extensive literature review and expert discussions, a semi-structured interview guide was developed for data collection (see online Supplemental File). Open-ended questions were preferred so as to provide interviewees with a maximum opportunity to express their views and help in gaining deeper understanding of issues (22,23). The initial version of the interview guide was discussed among the authors and was modified subsequently. In addition, pilot interviews were conducted with patients with HIV/AIDS. Finally, specific probes identified during pilot interviews were added to the interview guide prior to its final use.

Procedure and Interview Process

In-depth interviews were adopted for information gathering in view of the sensitivity of the subject and sociocultural context (23). All interviews were conducted by the principal investigator who went through significant training for qualitative methodology and interview process. Interviews were conducted in the English language as the majority of participants were comfortable with it; however, the Malay (national language) language was also used for patients who preferred it. Each interview lasted for approximately 25 to 65 minutes. All interviews were audio recorded by the principal investigator and the research assistant. Data collection process was further facilitated by taking field notes. 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. Patient demographics and disease-related data were also obtained prior to interviews.

Study Analysis

All transcribed interviews were subjected to thematic content analysis and the transcripts were analyzed for relevant content to identify the emerging themes (24). In order to obtain a sense of the whole, all transcripts were read several times. In order to maintain the integrity of the data, both manifest (identifying theme clusters) and latent (developing themes) were considered. Data were subjected to open coding, that is, collecting codes under potential subthemes comparing the themes clusters together and in relation to the entire data set to identify the emerging themes. All themes, initially identified by the principle investigator, were subjected to an independent review by an experienced qualitative researcher.

Study Trustworthiness

The trustworthiness was established at different phases of the study (25). During the data collection, field notes were taken and a reflective journal was maintained to address issues related to self-reflection and to reduce researcher bias (26). A purposive sampling was considered where the informants with best knowledge regarding the study questions were selected. In order to address the transferability of the data, participants' main characteristics were addressed so that the transferability of the data in other context can be addressed. In order to ensure the completeness and credibility of content analysis, the sample size was established based on saturation to maintain an optimal sample size. For this study, the unit of analysis was selected as sentences instead of letter or words to provide the relevant meaning of the text.

Ethical Approval

The study was carried out according to the principles expressed in the Helsinki Declaration. Ethical approvals by the Medical Research and Ethics Committee, Clinical Research Centre, and Ministry of Health Malaysia were taken. Finally, it was registered under National Medical Research Registry database (NMRR-12-411-12226).

Results

During the analysis, 2 theme clusters were merged, which were grouped into 10 emergent themes. Table 1 shows the thematic content analysis.

Table 1. Thematic Content Analysis Matrix.

Thematic Content Analysis Matrix	
Emergent Themes	Theme Cluster
Reasons for nonadherence	Disease (HIV)-induced hopelessness
	Lack of understanding and support
	Perceived and experience side effects
	Social and cultural influences
Ways to improve adherence	Education and motivation
	Sources of motivation
	Positive values
	Disciplined life style
	Peers and support groups
	Pill burden reduction

Reasons for Nonadherence

Disease (HIV)-induced hopelessness. It was found that a few participants described the gross negativity that comes to HIV/AIDS eventually turned into a state of hopelessness. These participants listed such negativities as an important aspect of nonadherence to ART.

> . . . the fear and the stigma, . . . the disempowerment that you get with HIV is so high, that you just don't care anymore . . . you just say "I've given up . . . I'm already HIV positive, I might as well just die" . . . The negativity that comes with HIV is so strong that you just don't feel you want to take any medication. (PT1)
>
> When you talk about medication or ART, it's long life. And you imagine, if we take the medication, if I myself take the medication every day at 8 o'clock . . . why I taking this medication, because I have a HIV . . . And, I think, is a very bad thing to tell myself I have HIV and I have to take it very long, I have to take it every day. And so far, it's not a curable disease. (PT2)
>
> Because they think they . . . will die, so they think they don't have to take medication, they are still going to die, if take medication also we will die, so they don't have to take medication. (PT13)

Lack of understanding and support. A few participants stated lack of understanding of disease and drugs as another major cause of nonadherence among PLWHA, which perhaps highlighted a need for patient education and awareness with a continuous support in order to optimize ART adherence among these patients. Nevertheless, such education should also target misconceptions toward disease and its treatment.

> I think, the main reason will be because first is they have lack of knowledge of this . . . medication, and then, they think that just a way to control . . . , disease. So, for certain people they think that it is useless . . . (PT3)
>
> Following because they, they have awareness, they know . . . dangerous of this disease, they understand fully, and . . . that is the first group. The second group . . . maybe they don't have a knowledge, and not much people support them, to offer information . . . (PT10)

> One thing is about the commitment to take the medication, because they feel afraid of to take the medication because commitment to take it for the rest of their life . . . (PT5)

Perceived and experience side effects. As expected, both perceived and experienced adverse drug reactions (ADRs) were found to be another possible cause of nonadherence, as it was earlier revealed that almost all patients had experienced some sort of ADRs while using ARTs.

> . . . nowadays people are very educated, they know everything about . . . , the medication produced, from various sort of toxics . . . chemicals which . . . give harm effect to our body . . . (PT2)
>
> . . . I realize that ARV cause me some time, . . . I'm not sure whether it's true or not, like the nightmare, and then the vivid dream sometime . . . because this thing for me is toxics . . . (PT4)

Social and cultural influences. Few of the patients described that their day-to-day social life affects medication compliance, as at times it is not easy for them to carry along or consume their medications due to fear of status disclosure. Also a few thought that some people do not believe in medications as such, it is not their culture to take something on a daily basis, therefore resulted in compliance issues.

> . . . but other people now don't know that he has (HIV) . . . , so sometimes when other people invite one out, or something, it's like quite difficult to . . . take at that time when he goes out with someone or family who doesn't know that he has it, it's quite difficult lah, to take the medications. (PT8)
>
> . . . It's a medication, so it's not a chicken or something, so it's not your culture to take medication, every day . . . (PT2)

Ways to Improve Adherence

Education and motivation. Patients described various possible ways, perhaps implementing them can result in better medication compliance among PLWHA. One of such measure is to increase patient education and trainings on diseases and medications, which will build up motivation between them. Such training should bring positive aspects in HIV treatment.

> What I'm looking for is also the thing other patients are looking for, of course the cure, treatment for this disease . . . we have to capture their attention . . . saying about . . . , the outcome of not taking the medication . . . , the risk of getting resistant . . . apart from the resistant, tolerance, something like that . . . (PT2)
>
> Treatment is not really challenges, because I have . . . few friends who are diabetes, injecting, and . . . cancer patient, you know, they go for chemo, ended up the hair all drop, and then they can't meet . . . everyone, because, other people can bring negative bacteria to them, this and that, but HIV person is not like that . . . (PT6)
>
> . . . those people have to motivate themselves. Some . . . motivation also cannot motivate others, because their reserve, they block themselves to receive anything . . . (PT4)

Sources of motivation. For sources of such motivation, many believed that it depends upon individuals; however, they also believed that doctors can play an important role in that, due to the fact that patients look into the doctor as second help after God.

> They have to find the right person . . . like my early stage doctor say, "If you do not taking this medication, your . . . lifespan is only 3 months. The doctor, normally people seeing doctor, . . . their thought the doctor is second God, they follow the doctor. (PT4)
>
> Sources of motivation, . . . I don't know lah, that really depends on the person himself, he needs to be able to come up with it. (PT8)

Positive values. Many of the participants also believed that in addition to other actions taken for improving medication adherence, a key element is having positive values inside. To them, patients with positive values will likely adhere more toward medications and hence there is perhaps a role of counselor or Health Care Professionals (HCPs) in general to provide assistance to these patients.

> I learn that from this infection, apparently I can be stronger and have more, you know, vision and even though I have lost err, some of my valuable persons next to me . . . (PT2)
>
> Because they . . . take it positively, they, want to make, they want to be more healthy as a person, so that's one of the reason. (PT5)

Disciplined life style. Participants also valued a need of more disciplined life among patients with HIV/AIDS. A life in which they have to realize the fact, as what they should be expecting out of this treatment, and put priority to medications. It also requires them to abandon such habits like "drug use," as this will continue to hinder medication adherence.

> . . . if we are not disciplined, meaning the virus will become, . . . will become resistant right, so meaning to say the medication, that we are taking will not be effective. So, we have to go through, we need to take the medication, then cost comes into play, and others too, so we need to adhere to the medication whether we want to or not. (PT8)
>
> . . . actually, . . . it isn't difficult to ensure that we take our medications daily . . . But sometimes it is our lifestyle that makes it inconvenient for us to follow the mediation instructions . . . for example, I will use the drug users as an example lah . . . a drug user, they cannot follow instructions on how to take their medications because there are other things more important to them, . . . let's suppose we're always careless and constantly leave the medications at home, because we have other things that are more important than the medications lah. (PT7)

Peers and support groups. Patients believed that peer and support groups can really play an important role in achieving adherence and dealing with the issue of noncompliance.

> ... they need to join the, the NGO forum, ... they understand, and they getting experience, and with the other people, ... (PT10)
>
> Counselling, there must be more effective counselling, can give someone to take their medications correctly ... sources of motivation like for me, I have in my community, I have that someone he has taken medication for 20 years, he is still alive like me; that is motivation for me. (PT13)

Pill burden reduction. A few participants also suggested that easing pill burden will help in dealing with issues of noncompliance among PLWHA.

> ... reduce, don't let it be so much, so once take 3,4 pills, so reduce it ... (PT13)

Discussion

An important aspect of participants' experiences and perspectives with HIV/AIDS treatment was adherence to the treatment, whereby they expressed reasons for nonadherence as well as viewed potential ways to improve patient adherence. Quality health-care outcomes are directly dependent on patient adherence, and nonadherence can be an inescapable threat not only to the patients' health and well-being but to overall outcomes of any treatment program, often resulting in economic burden. While no single interventional strategy can be used to improve the adherence of all patients, researches agreed that successful attempts to enhance adherence largely depend upon various factors (15). Therefore, adherence is not only limited to the way patients follow instructions toward the use of medication but also to overall retention to care, follow-up visits, and refilling of prescriptions (27). Such adherence requires greater social and contextual explanations which can help towards better understanding the sense of responsibility among patients, which is seen as a reciprocal response to help and support from family, support groups, care providers and other sources of supports, without this ART adherence may not be possible (27).

Adherence is a dire element for overall therapeutic success of an HIV treatment program and is often regarded as a determining factor of immunological and virological outcomes as well as drug resistance (28,29). The present study participants reported gross hopelessness due to the disease with a lack of support among the main reasons for poor adherence. It is believed that patients with HIV/AIDS often prefer nondisclosure of disease status, bearing all burden of disease as well as the self-perceived stigma which could have remarkable impact on overall well-being of these patients; nevertheless, such supports are fundamental in coping disease and providing sustained adherence (30). Psychological dynamics were also found linked to patients' decisions in seeking medical treatment, as it seems that no cure for the disease may result in state of hopelessness. Men et al found that patients with HIV/AIDS did not seek treatment even after 1 year of diagnosis due to the belief that he would not live very long (31). Patients' experienced side effects as well as lack of understanding toward disease and treatment were also perceived as important factors contributing toward nonadherence among Malaysian PLWHA. This was found almost similar to a recently published study which reported that side effects due to medications, lack of disease, and treatment knowledge as well as negative perceptions toward treatment were among the key elements to poor adherence (32), whereas perceived and experienced side effects, stigma, and status disclosure were reported barriers to adherence as reported by Mutwa et al (33). In fact side effects of antiretrovirals experienced by PLWHA are one of the most dominating clue to poor adherence explored by many studies around the world (32,34–38).

A qualitative review of factors affecting adherence among patients with HIV/AIDS has described sociodemographic, patient, disease, health-care system, and socioeconomic-related factors affecting patient adherence to the treatment (20). While quantitative studies have found similar factors, qualitative studies were helpful in exploring the meaning people give to such situations and are helpful in laying bare the processes that are at play in adherence (39). Cultural and belief influences are also important contributors to poor patient adherence which advocates a broader strategy in engaging patients with HIV/AIDS to optimize adherence (40–44). Participants suggested various ways to improve adherence, among them education, reduction in pill burden, and improved patient support were regarded as the key factors. In addition, the participants viewed doctors could play an exceptional role in improving adherence. This comes not as surprised as doctors or physicians are having an importantly indispensable role in overall patient care and hence patients often listen to them more than any other health-care provider, where studies have evaluated influences of physicians' characteristics on patient adherence (45). Similarly, reduction in pill burden has been found to have a significant impact on overall improvement in adherence and quality of life among patients with HIV/AIDS (46). As deemed by the participants, PLWHA require strong support from family, caregivers, and community and such supports also found to have a positive impact on overall patient adherence (47).

To abridge, adherence is a dynamic phenomenon, in which factors influencing varies over the time; thus, relevance of ongoing attention to adherence toward ARTs should have been given highest priority in any health-care system (20). In the developing world and the resource-limited countries, there isn't too much evidence available on how this important aspect is handled (11), making it essential for HCPs to acquire insight into possible influencing factors in each patient before and during the ART treatment (20). In managing HIV/AIDS, retention to care is fundamental, from both clinical outcome and public health point of view, and in the absence of any "gold standards" for the adherence measurement (48), health-care policy makers must devise mechanism contextual to the local setting.

Study Limitations and Future Research

Despite its importance and novelty in the local context, the present study had 2 main limitations. The study was conducted at a clinical facility which may had influenced patients' views on HIV treatment and care; in addition, the current study may not reflect the views of those defaulted hospital treatment or not receiving HIV care. More research is needed to gauge data from the above, not part of the hospital care, as well as some quantitative work to evaluate the generalizability of the issue and the associated factors.

Conclusions

To complement any HIV care program, retention to care and adherence to ARTs must be focused. Hopelessness, lack of social support, and poor doctor patient communication often force patients to bear disease burden affecting their social and psychological well-being. Among the factors highlighted, role of support group must be acknowledged in HIV/AIDS care.

Authors' Note

S.I.A. is the scientific coordinator and has developed the concept and made substantive intellectual contributions to the manuscript. All authors contributed to the concept and manuscript and final approval for manuscript submission.

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Supplemental Material

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