

A qualitative evaluation of patients' understanding, expectations and experiences with HIV/AIDS treatment

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Abstract

Background: Treatment understanding and experiences are vital to determine HIV patients' adherence and retention to care. **Methods:** In-depth patient interviews were audio-recorded, with a prior verbal and written consent and subjected to a thematic content analysis framework for data analysis. **Results:** Though majority of participants believed in Antiretroviral Therapy (ART) as the most effective way of treatment, they were greatly worried about its toxicities. Disease understanding and peer influence were regarded as the main reasons for treatment initiation; whereas, perceived side effects and lack of support system were among the main reasons associated with treatment delay. Almost all the patients experienced toxicities due to ARTs and viewed it negatively impacting their quality of life. **Conclusion:** It is vital for People Living with HIV/AIDS (PLWHA) to be retained in care; hence, the provision of optimal care with greater support to overcome treatment challenges must be focused in any HIV program.

Keywords: HIV & AIDS treatment, Qualitative exploration, Patients' understanding and experiences

INTRODUCTION

Human immunodeficiency virus (HIV) has been causing infections among the human population, ever since HIV/AIDS was first recognised as a separate medical entity in 1981 ^[1], and without any doubts, the modern medical history may not have witnessed any similar disease or illness which is inter-connected to many aspects of the human life ^[2]. However, extraordinary efforts in all aspects of medical sciences and patient care have made it possible for HIV infection to be a chronic manageable disease ^[3]. While on the global agenda zero discrimination, 90:90:90 treatments for all and elimination of HIV by 2030 are on the top ^[4], it is the developing world facing considerable challenges in managing both the social and health impacts of the disease.

With the shift of HIV as a chronic disease, it is imperative for the patient to remain on HIV treatment for an indefinite period ^[5]. This requires patients' strict adherence to the antiretroviral therapy (ART); nonetheless, researches around the world have reported that antiretroviral medications cause both short-and long-term adverse drug reactions (ADRs), which may not only affect patients' quality of life but also creates greater issues of compliance and retention to medical care ^[6]. It is well understood that patients suffering from chronic illnesses are likely to encounter increasingly complex challenges, given the fact that they require indefinite long-term treatment care. These challenges may often result in delayed treatment, inappropriate healthcare-seeking

behaviors, as well as poor compliance to the treatment or even a decision to forego treatment ^[7].

Lack of information and understanding about disease and medicines use have been reported as common factors affecting HIV patients' compliance towards prescribed medications ^[8,9]. Likewise, misunderstandings and improper information about ARTs could also contribute towards the incorrect use of medications, increasing the possibility of non-adherence and therapeutic failure. Conversely, patients with proper understanding and information on treatment are likely to be more compliant, maintaining the quantity and quality of information for patients' decision on their treatment ^[8]. It is thus vital for all healthcare professionals

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involved in HIV care to ensure the provision of effective and efficient quality information on the prescribed medications, and to engage with the patients on their medication-related issues to foster improved compliance^[10].

Many barriers, including mental health, substance abuse, beliefs and understanding towards HIV/AIDS treatment, treatment complexities, side effects, and lack of social support resulted in poor patient adherence^[11, 12]. In addition, perceptions of necessity of treatment and concerns about potential ADRs, resulted in a significant decline in adherence over time^[13]. Therefore, qualitative research is gaining more popularity in the medical research forefront, particularly for HIV/AIDS-related outcomes^[14, 15] and undeniably, these research outcomes are fundamental for our understanding towards the social and behavioral aspects of HIV and AIDS^[16]. Moreover, patients' prospects towards disease and its treatment have also been noted to affect their health-related quality of life^[17].

In Malaysia, the number of HIV/AIDS cases is on a rise but little is known on the patients' beliefs about their disease, perceptions of the effectiveness of the treatment, and perceptions on severity of the side effects of ARTs. The current study aims to evaluate these issues through a qualitative investigation.

METHODS

Design and setting

A qualitative "Phenomenological approach" was adopted to better understand the study objectives, and to explore the needs for future interventions. This study was conducted in line with the principles of Helsinki Declaration, and upon obtaining necessary approvals from the Medical Research & Ethics Committee (MREC) and Clinical Research Centre (CRC), Ministry of Health, Malaysia. It was then registered under the National Medical Research Registry (NMRR) database. The study site chosen was the largest referral centre for infectious diseases in the country, i.e. Hospital Sungai Buloh, to allow for access of the model of the best practice.

The Participants

The study participants were Malaysian adults aged 18 years or older, diagnosed with HIV/AIDS, and were attending outpatient infectious disease clinics at Hospital Sungai Buloh, Malaysia. All participants were provided with study information sheets in both Malay (National Language) and English languages; while, verbal information was also disseminated to participants on an as-needed basis. Following the provision of study objectives and prior to data collection, both written and verbal consents were obtained from all study participants. Fifteen participants were approached for interviews; there was no new information that was obtained at the 13th interview and hence a saturation point was believed to have been achieved at this point. This number also fulfils

the required sample size for phenomenological approaches.^[18]

Study Tool

For the purpose of data collection, a semi-structured interview guide was developed after an extensive literature review and discussions with experts in the field. The interview guide consists of possible questions to assess the patients' expectations, understandings and experiences with ARTs. Most of the questions were open-ended, as these questions provide maximum opportunity for expression of views, this will allow for a deeper understanding of the related issues^[19, 20]. The preliminary draft interview-guide was discussed among the authors and was modified after a few rounds of discussions. However, to ensure that the set of questions developed were useful in the objective information retrieval, pilot interviews were conducted with HIV/AIDS patients. The draft interview guide was then modified based on specific probes identified during the pilot interviews.

Procedure and Interview process

In view of the sensitivity of the subject and socio-cultural context, in-depth-interviews were adopted for data collection^[20]. Interviews were conducted in both the English and Malay languages (approximately 25-65 minutes each). All interviews were attended by the principal investigator along with a research assistant (to take field notes and facilitate the interview process), and were audio-recorded. Verbatim transcriptions for individual interview sessions were shared with the respective study participants for their approval. Additional information like participants' demographics and relevant clinical data were also recorded from the participants' clinical notes. Finally, upon receiving approvals for the verbatim transcriptions, the data was analysed with a thematic content analysis framework to aid in identification of the emerging categories (themes)^[21]. All themes, initially identified by the principle investigator, were subjected to an independent review by an experienced qualitative researcher.

RESULTS

During the analysis, thirteen emerged themes were grouped into six theme clusters. Table 1 shows the thematic content analysis.

Table 1. Thematic content analysis matrix

Theme cluster	Emerged themes
Knowledge of HIV Treatment	<ul style="list-style-type: none"> Perceived curability of HIV/AIDS
Non-Medicated ways of HIV management	<ul style="list-style-type: none"> Perceived effectiveness of life style changes Beliefs in divine help
Beliefs and understanding towards ARTs	<ul style="list-style-type: none"> Perceived effectiveness
Reasons to start ART	<ul style="list-style-type: none"> Peer influence and beliefs

	<ul style="list-style-type: none"> • Disease understanding and positive values
Reasons to delay ART	<ul style="list-style-type: none"> • Fear of side effects <ul style="list-style-type: none"> • Lack of support • Negative values • Delay in accepting status
Experiences with ART	<ul style="list-style-type: none"> • Pill burden • Unwanted effects • Impact of ADRs on well-being

Knowledge of HIV treatment

- **Perceived curability of HIV/AIDS**

Most of the patients were aware about ARTs as a treatment option for HIV/AIDS. They also believed that although these drugs may not completely cure HIV/AIDS, their lifespan may be increased by using these medications. Interestingly a few patients kept themselves updated regarding current HIV treatment options available globally and are hopeful that there will be a cure to the disease.

“Not completely, but we can do a lot...we can do some treatment, so we can live longer and..... We can treat it, but we cannot kill the virus” (PT3).

I think can, soon, because.... in other country they have a report saying they have a cure about HIV....AIDS; have two cases, one is a guy....but one is baby, the mother have HIV.....she already give the HAART, ART treatment. So after 3 years, the baby is fully cured...” (PT9).

Non-medicated ways of HIV management

- **Perceived effectiveness of lifestyle changes**

Although they were aware that HIV/AIDS is not completely curable, most of the participants strongly believed that adopting a healthy lifestyle will somehow be beneficial in managing the disease.

“I’ll just get really healthy making sure I’ve got clean water, clean air, I’m living an environment that’s not polluted....., do a lot of exercise.” (PT1)

Positive-thinking was perceived as a way of life for some participants to stay healthy and boost their immune system. A generalised positive optimism towards healthy living played an important role in some of the patients’ treatment decision-making process as they decided to forgo their modern medicines in treating HIV/AIDS; they merely relied on lifestyle changes as a cure for their disease.

“.....I really take care of myself, like, I sleep 8 hours, I eat healthy food, and then always positive thinking, that practice make me live fifteen years without medication,....” (PT6)

- **Beliefs in divine help**

Spiritual attributes were also closely associated with HIV, in which some participants were of strong opinions that besides taking medications and living healthily, praying to God while asking for forgiveness will assist in managing the disease. Such beliefs highlighted the greater importance of spirituality in the overall management of the disease among Malaysian HIV/AIDS patients.

“Yes, I think, for us, as Muslim I think we believe that, there is a beside medication right! If you pray God, and then you change your lifestyle, you really.....regret whatever you did, and I believe anything can happen.” (PT10)

Beliefs and understanding towards ARTs

- **Perceived effectiveness**

Most participants were grounded in their belief of the effectiveness of antiretroviral therapy. The patients generally believed that medications provided by the doctors or hospitals are the best treatment options for HIV that can prolong their life span.

“I know ART is available, and I know that ART can be quite successful in many cases. I think, if I’m not mistaken there’s like 60% success rate, but I’m not 100% sure about..... I haven’t heard of any other drug.....Some have survived, some have not....” (PT1)

However, despite such viewpoints, a few were sceptical about the benefits of ARTs, as to them, they will eventually die from this disease.

“I am going to pass away,.... some more what for want to take all this things? (PT12)

Despite strong beliefs in the effectiveness of ARTs, most patients were concerned about the side effects and toxicities caused by the medications.

“.....there are drugs available, although the drugs are horrible. I mean, I think doctors don’t actually tell you how horrible these drugs can be ,.....I don’t want to go on ART because I know that these drugs have got really horrible side effects,....” (PT1)

Reasons to start ART

- **Peer influence and beliefs**

Most of the participants specified personal belief and strong influence from peers’ (HIV infected individuals) experiences as main contributory factors in commencing antiretroviral treatment. In addition, clear views and understanding of the disease progression, and positive patient values were also associated with the decision to commence antiretroviral treatment.

"...some people say, if we don't have... the treatment, maybe we can stay... 5 years or more, or 10 years. If we have treatment, maybe we can stay 20 years or 30 years, so it makes us to... ." (PT9)

- **Disease understanding and positive values**

".....I'm not gonna let discrimination or stigma get in the way of my life....." (PT1)

"It takes me a year and a half, after I was diagnosed. In the beginning yes, but I think positive... that sooner or later I need to take it, because it's all about my health... ." (PT5)

Reasons to delay ART

- **Fear of side effects**

A handful of patients delayed antiretroviral treatment due to potential side effects. These patients were fearful of adverse drug events and were sceptical on the effectiveness of these medications. Some patients stated that sharing of treatment experiences may pose a greater challenge to commence ARTs as such sharing may involve negative and unpleasant experiences too.

"They said it was a terrible experience to have this ART...they have mentioned that when they use this Stocrin, they experience this nightmare, and.....I found scary as well to initiate ART at this time." (PT2)

"...fears about,.....that's why I hate people say 'Sharing is Caring'.....When people talk about.....sharing about side effect medication, actually sharing is killing people, those who are newly diagnosed..." (PT4)

- **Lack of support**

Some of the patients found that the lack of support groups, especially in terms of treatment related issues was one of the reasons for treatment delays, since they don't acquire the support they require.

"... is quite difficult to find a support group, then I have to struggle myself, and... not much information was also available, so. Yeah. Not much information and those, last time, I have to struggle.... ." (PT4)

- **Negative values**

Negative perceptions about antiretroviral treatment and negative patient values also contributed to treatment delays. Such negative values could be accountable for a greater impact of HIV/AIDS on patients' quality of life.

"...because of the negative values inside them. They lost hope...There are a lot of problems, and maybe at certain stages, you feel you are useless and all that right, there is a negative value still on you because you are being diagnosed without notice." (PT11)

- **Delay in accepting status**

For some patients, the sudden news of being 'HIV positive' greatly impacts a patient's life that it eventually takes time before they accept their status and commence treatment.

"I believe every people who just know they're positive, they will be in shock, cannot accept and lastly, they will accept eventually. So, during this period...you know, different period they will have different barriers..." (PT2)

"I believe every patient when they first diagnose, they don't think about (treatment), they don't think about seeing a doctor. The first thing that come to the mind, 'Shit happens' so now how am I going to deal with my wife, my parents? It's a shock phase.....with that, for a long time to accept, and only after they accept it, they will, you know, 'what option do I have?' And by the time when... It is already too late, you know..." (PT2)

Experiences with ART

- **Pill Burden**

The patients shared their experiences with antiretroviral treatment, some of which were concerns regarding pill burden, both in terms of the number of tablets as well as the frequency of therapy. Most patients faced challenges, especially in the beginning of the treatment since the medications have to be taken on a daily basis. Of course, these medications are not limited to ARTs only, but include multivitamins, antibiotics and other medications for alleviation of various symptoms due to the disease. The patients also found it challenging to carry around and consume their ARTs during their routine social life, due to perceived stigma in the community.

"The frequency, the scheduling of the treatment ...Yeah that's what I mean. So that can be complicated in that sense...there's an issue of stigma of course, you know you're worried that people will find out that you're taking all these drugs, and most probably you're HIV positive.....That's the second thing." (PT1)

"...In beginning back to early stage, I have to take 5 pills at night and 2 pills in the morning, so altogether 7 pills.....There are other multivitamins that I have to take." (PT4)

Some patients were also of the notion that the pill burden is hazardous to the body.

"I not think so lah, lot of medicine take also not good, no point lah.....but reduce the medicine lah, you know, cannot eat too much medicine also." (PT12)

- **Unwanted effects**

Almost all patients undergoing antiretroviral treatment experienced unwanted adverse effects. These reported side

effects range from skin rashes, nausea, vomiting, diarrhoea, dizziness, confusion, sleep disturbances and nightmares, which were intolerable and resulted in a lot of inconvenience. According to them, they were either given medications to treat these unwanted effects or were informed by their doctors that these are normal expected effects of the medications that one has to live with.

"...The side effects are really quite bad..., the discoloration in your face..... especially that thing that you get on your face, that kind of burnt look..... One is because the treatment is really complicated. Another thing is the side effects is really terrible." (PT1)

"Stocrin and Combivir...make people feel want to vomit, and actually I have this medicine for one month, and every day I feel want to vomit.It makes you feel uncomfortable." (PT9)

"I failed the Nivirapine, a week after taking the medication; I failed.....rash on my whole body."(PT13)

• Impact of ADRs on well-being

Although some patients managed to tolerate the side effects of ARTs, a handful shared the devastating impact of these side effects on their daily routine. They perceived negative impacts in their physical, mental and social well-being due to these effects. A few even experienced suicidal thoughts and decided to discontinue their medications as they preferred faster death over the unbearable impact of ARTs.

"ART....makes me very sad, makes me like want to suicide, you know, the side effect is very hard.....Is the diarrhoea, one in a half month, and.....my weight is going down, 52 to 46 now,.....and then I don't have.... freedom what to eat" (PT6)

"I will feel quite suffer to have the treatment because I said I have the vomit (side effect) for it...., sometime I decided to stop the medicine, but I'm, I will scare if I stop the treatment.....maybe I will die faster than....."(PT9)

DISCUSSION

Malaysian HIV/AIDS patients were of the mind-set that antiretroviral medications are the only and most effective available treatment for HIV/AIDS. Though these patients were generally unable to comprehend if HIV/AIDS is manageable, they were aware that ARTs can help them live longer. The findings are considerably reasonable as the patients felt that the lack of understanding and incorrect beliefs in antiretroviral treatment can result in improper use of medications and adherence issues, eventually leading to therapeutic failure^[8,9]. For chronic diseases, practical health literateness has strong connections with disease-related knowledge and understanding, and treatment perceptions^[22]; hence, there is a greater need for strong beliefs and understanding towards ARTs. Improved understanding of

medications facilitates the discourse between patients and health care professionals (HCPs), cultivates an active participation of the user about own health, and this positively influences treatment adherence and ultimately improves therapeutic outcomes^[8].

It is also interesting to note that strong cultural beliefs influenced PLWHA to resort to divine help as a solution to the disease. In addition, the participants believed that practicing a healthy lifestyle will complement their antiretroviral therapy outcomes. In the history of mankind, spirituality has a strong relationship with chronic diseases such as cancer, heart disease, neurological problems and kidney diseases^[23]. Similar studies have found constructive outcomes of such beliefs among HIV/AIDS patients, in terms of improved quality of life^[24] as well as slowing disease progression^[25]. However, such cultural beliefs are often regarded as barriers towards adherence^[9,26]. A South African study identified a deeply entwined spirituality among PLWHA, whereby participants believed strongly in divine help that would permit them to live stronger and longer despite having HIV/AIDS^[23]. These findings iterate the need for spiritual assessments and its implications on HIV/AIDS treatment program.

In addition, although the healthy lifestyles adopted by patients may not directly influence their HIV treatment, it could have a significant impact on their overall disease management. Sikkema *et al.* found that HIV-related symptoms, shame, coping style, and substance use have significant associations with sexual risk behaviour among HIV individuals, whereby enhanced coping skills could help in preventing these behaviours^[27]. Similarly, it was also concluded in a study that exercise can possibly benefit HIV treatment by managing disease symptoms as well as ADRs experienced by the patients^[28]. The importance of being aware of patients' perceptions towards ARTs should be paramount in any HIV care program. In the present study, one of the key aspects of patients' understanding towards treatment was noted as the perceived fear of side effects caused by antiretroviral treatment. A number of studies have reported negative perceptions towards ARTs that include ADRs as the most common cause of refusal to commence ARTs and non-adherence to the treatment^[13, 29-35]. Additionally, treatment beliefs have been highlighted as an important factor to sexual risk behaviour^[36], making assessments of such beliefs and perceptions extremely important as to which strategies should be implemented to improvise existing interventional programs in order to better manage the challenges of adherence and retention to care.

Patients' experience with disease and associated treatment was another important theme that emerged during the analysis. When elucidating their experiences with the disease, the participants identified significant impacts of HIV on their routine activities and overall well-being, in particular physical, mental and emotional well-being. In addition, deterioration of work efficiency and social isolation were also

included among such experiences by PLWHA. Such claims appeared analogous to a study which concluded that psychological and social well-being were affected more than physical well-being among PLWHA in Malaysia [2]. Poor perceived and reported HRQoL have been widely established and is a well-known phenomenon among PLWHA [37]. Living with a chronic disease such as HIV/AIDS and an ongoing struggle for better care definitely results in negative impacts and greater challenges for these individuals [7]. Penedo *et al.* concluded that personality traits were closely associated with quality of life among PLWHA, which in turn may affect treatment adherence [38]. Both disease and its treatment-related factors could be held accountable for decreased work efficiency; nutritional issues of HIV/AIDS depletion of folic acid and vitamin B₁₂ causes anaemia that decreases work endurance among PLWHA [39]. As far as social isolation is concerned, it is a well-known issue tagged with stigma and discrimination generated by the disease [15, 23, 40-42]. In line with the change of status in PLWHA, they require changes in physical health, psychological functioning, social relations, and adoption of disease-specific regimens throughout their life span [43]; hence, continuous support to them is crucial in managing HIV with ARTs.

An overall positive value that includes understanding towards the disease and its treatment with the patients' peer influences were regarded as major reasons to start ARTs. A qualitative exploration of Australian HIV/AIDS patients has found a number of reasons that resulted in treatment delay and these include fear of side effects; the perceived inconvenience of the treatment and beliefs that there was no reason to start therapy in the absence of AIDS-related symptoms [35]. Interestingly, a Polish study revealed fear of side effects as well as patients' self-perceptions that they were not candidates for ARTs, as most prevalent reasons to delay their ART treatment [32]. Perceived side effects of the treatment alone were regarded as important factors in delaying treatment and it is not limited to HIV/AIDS. A recently published Malaysian study among Cancer patients also found similar reasons for the delay [44], emphasizing the need for greater patient and care giver discussions in explaining the importance of treatment. Such fears were also reported as the key to care failure [26, 29]. The diagnosis of diseases like HIV/AIDS encompasses a state of shock, sadness and guilt for which these patients were never prepared and such situations can often lead to difficulty in accepting the status [40].

Although many patients believed in the effectiveness and need of ARTs for the management of HIV/AIDS, they shared their difficulties in compliance due to the pill burden, side effects and negative impact of ARTs on quality of life. Antiretroviral medications result in a range of short term and long term toxicities [45]. The absence of cure for HIV/AIDS results in a continued experience of uncomfortable side effects that not only decrease quality of life [46] but also causes genuine issues of retention to care and long terms adherence [47]. A qualitative finding of psychosocial impact

of lipodystrophy, a commonly associated side effect of ART, depicted that lipodystrophy had physical and psychological effects, ranging from bodily discomfort to low self-esteem and depression. The study recommended that HCPs take notice of such ADRs before it results in non-adherence [48]. Studies have reported that almost 90% of patients on HAART had experienced side effects [49], highlighting the importance of this issue to both patients as well as HCPs. The greater issue of adherence to ARTs have been evaluated by a number of quantitative studies, and ADRs have consistently been reported as one of the most common factors associated with poor adherence [50]. This highlights the importance of addressing the issue through multi facet approaches involving all HCPs. These particular experiences while highlighting the patients challenges, also emphasize the greater role of pharmacists in providing pharmaceutical care with regards to reducing the pill burden, and dose frequencies, and minimizing ADRs and drug interactions, to improve overall adherence and treatment outcomes [51].

Study limitations:

As the study took place at a hospital (clinical setting), this may have influenced the patients' perceptions and views on the subject matter. The findings may not represent PLWHA who are not receiving any medical care.

CONCLUSION

Qualitative explorations can provide meaningful insights on patients' understandings and experiences with the disease and associated treatment. These insights are helpful in devising strategies to optimise patient care. It is vital for people living with HIV/AIDS (PLWHA) to be retained in care. Hence, the provision of optimal care with greater support to overcome treatment challenges must be focused in any HIV program.

Key Considerations

- Lack of treatment understandings and misconceptions could lead to therapeutic challenges.
- HIV patients have many misunderstandings towards ARTs, in addition their experiences with these medications are often not explored.
- Qualitative methods can help explore the real challenges faced by HIV patients with regards to ARTs.
- These findings could help in scrutinizing the existing strategies and devising effective plans towards medication-related issues, including adherence and retention to care.

Authors' Contribution:

SIA is the scientific coordinator of this study and has developed the concept and made substantive intellectual contributions to the manuscript. All authors contributed to the study concept and design, manuscript revision for intellectual concepts and final approval for manuscript submission.

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The authors declare no conflict of interest.

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