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Original Research

Lived Experience of People Living with HIV/AIDS Undergoing Antiretroviral Therapy: A Qualitative Study

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ABSTRACT

Introduction: Antiretroviral therapy is an important factor in improving the quality of life of HIV sufferers, but a complex problem in HIV sufferers is a trigger factor for non-compliance in undergoing ARV therapy. The purpose of this study was to explore the experience of people living with HIV/AIDS (PLWHA) undergoing antiretroviral treatment.

Methods: This study was a qualitative phenomenological study, with a sample of 13 HIV patients (10 men and 3 women) who were taking antiretroviral therapy for more than one year; they were recruited using purposive sampling techniques, and data were collected through in-depth semi-structured interviews, field notes and document reviews. Data were analyzed using the Colaizzi method which consists of nine stages.

Results: There were six themes that emerged from the experience of PLWHA undergoing antiretroviral therapy and these became the subject of this study, namely knowledge of HIV disease and antiretroviral drugs, self-motivation, social support, and skills in undergoing treatment (self-management), adherence, and quality of life.

Conclusion: Of the six themes that emerged, poor knowledge (understanding of the disease and its treatment), social support and self-management were the main factors that were obstacles to and causes of treatment failure; this was due to the unpreparedness for receiving information at the beginning of treatment, lack of motivation, and ignorance in behavior when people had problems with medication.

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INTRODUCTION

HIV patients' adherence to antiretroviral therapy (ARV) is an important mechanism for preventing HIV transmission (Zulliger, Barrington, Donastorg, Perez, & Kerrigan, 2015),but people living with HIV/AIDS (PLWHA) often disappear during the course of HIV treatment. Various precipitating factors cause non-adherence to antiretroviral therapy, but the main factors of non-compliance until now have not yet been known with certainty. Indonesia has been conducting free treatment for PLWHA since 2004, and various counseling has been conducted to improve HIV patient adherence to ARVs, but non-compliance with ARVs is still a problem in Indonesia. This is evidenced by the Lost Follow Up (LFU) rates for ARV care and therapy Which are quite high at 21.87% (Kementerian Kesehatan RI, 2018). Non-compliance with treatment is a major factor in treatment failure in PLWHA. The effect of non-compliance can affect the quality of life of people with HIV because it will cause resistance and disease progression to death (Capetti & Rizzardini, 2019). Decreased quality of life that occurs in HIV patients is not only caused by compliance but also due to illness and depression (Mwesiga et al., 2015).

PLWHA are increasing every year; currently more than 36.9 million people worldwide suffer from HIV and Indonesia is one of the Asian countries with a rapidly growing rate of Human Immuno-deficiency Virus (HIV) infection (UNAIDS, 2018). East Java occupies the first position in Indonesia with the highest incidence of HIV in 2017 followed by Jakarta and Central Java (Kementerian Kesehatan RI, 2018). According to a report on HIV care and antiretroviral therapy in 2017, there were around 214,819 people who were eligible for ARVs, but only 180,843 people had received ARVs. Out of 180,843 people who had received ARV therapy 39,542 people (21.87%) had been lost to follow-up (21.87%) LFU) and 3,501 (1.93%) stopped taking ARV.

Antiretroviral therapy (ART) is a very important factor for improving the quality of life of PLWHA; complex problems that occur in PLWHA are a trigger for non-compliance in undergoing ARV therapy (Lindayani, Chen, Wang, & Ko, 2018). Quality of Life is a multi-dimensional and dynamic concept, which reflects the non-biomedical perspective of HIV treatment, combining important subjective assessments on various aspects of individual well-being, including physical, functional, social, emotional and even spiritual well-being (Tomita et al., 2014). The experience of PLWHA during ART treatment changes over time. PLWHA stated that support from health workers or others greatly affected their adherence to ART (Hendrickson et al., 2019). Social care, the home environment, finances, freedom, and opportunities to obtain information related to ARV treatment get the lowest score that adversely affects the quality of life of PLWHA (Ndubuka, Lim, Ehlers, & Van Der Wal, 2017). Subjective support and the use of social support and knowledge are very influential in improving the quality of life of PLWHA (Liu, Qu, Zhu, & Hu, 2015), Research (Lan et al., 2015)states that low social support has reduced the quality of life of PLWHA. Counseling is also one way to improve adherence to ARVs and the quality of life of PLWHA.

The information has an important role in PLWHA in undergoing lifelong HIV care, but information alone is not enough to make PLWHA have good compliance and good quality of life. According to (Nelson et al., 2018)adherence in undergoing ART treatment is determined by three factors namely: information, motivation and behavioral skills. If there are obstacles in one of these components, it can reduce the possibility of behavior that is compliant or consistent with treatment. The information in question is an understanding of the disease, the use of drugs and drug reactions; motivation includes self motivation and social support. Motivation is needed in ART treatment adherence; without motivation ART treatment cannot be continued (Nursalam, K, Misutarno, & S, 2018). Behavioral skills in creating good adherence are seen from the ability to obtain drugs, take medication regularly and the ability to cope with or minimize the side effects of drugs that are uncomfortable in the body.

Previous research has discussed the experience of HIV sufferers in undergoing treatment extensively, but a specifically discussion of behavioral skills based on the information theory of motivational behavioral skills (IMB) has never been undertaken before, so in this study more discussed about behavioral skills to still be able to maintain adherence and improve quality of life for the better. This study aims to describe what experiences HIV sufferers face during their ART treatment using a qualitative research method with a phenomenological approach. Identified factors are expected to be input and learning for health workers in providing appropriate nursing care

MATERIALS AND METHODS

Research Design

This research was qualitative based on an interpretive phenomenological approach. The design was used to answer the research objectives in obtaining the meaning of the experience of the research subjects while undergoing antiretroviral therapy.

Participants and Recuitment

The population is PLWHA at Sidoarjo Hospital, Indonesia. This study involved 13 PLWHA as participants obtained using a purposive sampling technique. The inclusion criteria were PLWHA who had taken ART for more than one year, were over 20 years old, were cooperative, and were not pregnant women. Participants were recruited based on ethical principles. Participants involved in previous studies have received written explanations regarding the research objectives, procedures, rights and obligations, benefits and losses during the study. Only participants who have given informed consent are involved in this research. This research obtained ethical approval from the Ethical committee of Sidoarjo Hospital, approval number 893.3 / 0059 / 438.6.7/2020

Data Collection and Analysis

Before starting the data collection, the researchers framed interview guidelines and tried out three participants to validate questions. Data were collected through in-depth interviews using semi-structured interview guides and completed with field notes Formal interviews were conducted with participants and took 20-40 min for each participant. The interview started with these questions: "How was your experience while on antiretroviral treatment?", "Try to tell me your health condition in the past year?", "What is your attitude when given an explanation by health workers regarding lifelong HIV treatment?", and covered "Treatment-related information", "Personal motivation barriers", "Social Motivation barriers", and "Behavioral skills barriers". Questions were open-ended and interviews were recorded by a voice recorder. The interview process was carried out until no new data were found. Interview results were written up as verbatim transcripts and this was done after each interview was completed with one participant. Regular discussion between the three researchers was conducted to integrate the research findings.

Table 1 Characteristics of Participants

No	N	Gender	Age(Year)	Antiretroviral(year)	Occupation	Education
1	P1	Male	42	4	Self-employment	Senior High
2	P2	Male	41	13	Self-employment	Senior High
3	P3	Male	34	5	Civil-government	Senior High
4	P4	Male	30	5	Self-employment	University
5	P5	Female	29	2	No work	Senior High
6	P6	Male	31	5	Security	Senior High
7	P7	Male	47	2	Trader	Junior High
8	P8	Male	30	5	Driver	Senior High
9	P9	Male	50	5	Self-employment	Senior High
10	P10	Male	30	5	Self-employment	Senior High
11	P11	Male	27	2	Self-employment	Senior High
12	P12	Female	51	4	No Work	Senior High
13	P13	Female	49	5	Self-employment	Elementary

Risk factors for family resilience were analyzed and interpreted using analytic analysis according to Collaizi consisting of nine steps. The analysis included: 1) describing phenomena to be studied; 2) collecting descriptions of phenomena through participants' opinions; 3) reading the entire description of phenomena submitted by participants; 4) re-reading interview transcripts and citing meaningful statements; 5) making outlines of meaningful statements; 6) organizing collections of meanings formulated into groups of themes; 7) writing complete descriptions; 8) meeting participants to validate the compiled descriptions; and 9) incorporating validation results data into full descriptions. Data collection was conducted simultaneously with the data analysis process until data saturation occurred. Demographic data were described and presented in the table of participants' characteristics.

RESULTS

Demographic Data

Descriptive statistics of the characteristics of participants are shown in Table 1. This study included 13 PLWHA who were taking ART (3 females and 10 males), aged within the range of 22-51 years. The educational level of participants varied from elementary school to university. The majority of participants (11 people) were working, as civil servants, self-employed, traders, security, and a driver, while two people were not working. Most of the participants tok the fixed dose combination (FDC) of antiretroviral drugs (9 people), 2 people were duviral-neviral and 1 person was TLE. The average duration of drug consumption was between two and five years, and one person had been taking them for 13 years.

Overview of Undergoing ART Treatment Process

Six themes are extraced from the experience of PLWHA regarding the process of undergoing ART treatment. The themes were knowledge, self-motivation, social support, behavioral skills, adherence, and quality of life (Table 2). The details of each theme are described.

Knowledge

The theme of knowledge in this study includes the understanding of PLWHA related to the disease and its treatment. This knowledge theme was identified through sub-themes : 1) health education, 2) information providers, and patient experience. Participants were given information related to how to take medicine, that it must be taken on time and routinely for a lifetime. Sometimes participants were still often too late to take medicine, and there were those who already felt healthy who stopped taking medicine. There were participants who stated that they did not really understand the drugs and their effects if they stopped, those who did not understand the reasons when given information related to the disease and the medicine who were not in a mental condition of readiness, so they could not understand the explanation given very well. Initially uncomfortable drug reactions in the body sometimes become an inhibiting factor for taking medication on time. The following is a participant quote :

> *"I was first informed when I started taking ART, but I didn't really understand at the time because I still didn't accept my condition at that time"*(P13)

Self-motivation

Self-motivation is the support of yourself to be able to do the best thing. This theme was identified through the sub-themes: 1) perceived effects, 2) loved ones. The first effects felt by the participants when taking medication were mostly dizziness, nauseous, and weakness, but these were only temporary; the effect disappeared by itself. The participants who felt healthier after taking medicine regularly became convinced that the medicine they took had good benefits for them. Children, wives or parents also were a separate motivation for PLWHA, in terms of wanting to be happy and wanting to see children grow up well; this was one of the reasons for PLWHA routinely taking medicine regularly.

Table 2. Identification of the Description of the Process of Undergoing ART for PLWHA

Theme	Sub-theme	Significant Statement
Knowledge	Health education - How to take medicine	'Don't be late ... and at the same time …if the medicine comes out then I have to take more medicine until the medicine comes in ...' (P2) (P5) (P10)
	- Drug reaction	'I am dizzy when I woke up .... I felt I lost concentration' (P7) (P8)
	Information provider - Health workers	'First I was given an ARV drug I was given an explanation by the nurse ... doctor ...' (P5) (P9) (P13)
	- Media	'I got that information only verbally ...' (P8) (P9) (P13)
	- PLWHA companion	'from companion ODHA' (P7) (P10)
Self-motivation	Effects that are felt	'After taking medicine regularly I never drop ... I want to be healthy ... I used to be very weak ...' (P1) (P9)
		'I have 1 CD4 left ... and I have been hospitalized for a long time ... after my CD4 ART consumption has increased ...' (P2)
	People who loved	'My child is still small…need money ... I want to see my child grow up ...' (p7) (P2)
		'I want to be healthy so I can help my parents ... I want to get married ...' (P10) (P6)
Social support	Family - Instrumental support	'If I don't have time to take medicine ... I am assisted by my family to get the medicine ... I was taken by my husband or driver ...' (P9) (P2)
		'I have in a pillbox so that it's easy to remember taking medication' (P5)
	- Information support	'My child always reminds me, don't forget to take medicine when you have a little ...' (P2) (P9)
	Fellow HIV patients	' I get a solution from a fellow HIV friend to help solve my problem … I am reminded by my friend to take medicine' (P10) (P2).
Disease management skills	Efforts to minimize side effects	''I always eat before taking medicine so I don't feel sick, I also eat dry bread to avoid nausea when taking medicine ... if I get dizzy, I immediately go to sleep' (P5) (P13)
		'I was always dizzy when I woke up ... and it bothers me to work ... I used to drink at 9 p.m.'(P7)
	Efforts to obtain drugs	'I always ask once for permission to take medicine ... replace with my fellow PLWHA to take medicine ...' (P10) (P9)
	Efforts to take medicine according to rules	'I always take medicine when I get a day off' (P6).
		'Use a mobile alarm... carry medicine wherever I go ...' (P3) (P8)
		'I take it every night when I go to sleep' (P10)
Adherence	Motivation - Personal	'I have seen people who often drop because they are not compliant to take ART ... and I don't want to be like that' (P9)
		'I must be healthy and live longer for my children and family' (P2)
	- Health Officer Information	'The nurse said that she should take the medication routinely and regularly, if not later the medicine will be resistant ...' (P4)
		'if you don't obey, you will easily get the disease ... later you will get OI, so ... I just obey, I don't want to add disease' (P11)
	- Social (family and peers)	'My mother always calls the phone every time she has taken medicine or not' (P4)
	Behavior	'I joined an ODHA organization ... there I got a lot of knowledge about my illness ... and many gave me motivation to stay motivated' (P10)
		'I was nauseous and wanted to vomit after a while taking medicine ... then I tried eating before taking medicine ... and eating dry bread after taking medicine' (P5) 'Wherever I go, I always carry my medicines ..., I put my medicine in a small place' (P11) (P12)
Quality of life	Physical health aspects	'Before going to bed I take ART medicine ... but every morning when I take ART medicine at night I feel weak and have difficulty waking up' (P3) 'After a while I take ART medication I feel dizzy ... when I get dizzy I can only lie down, can't go anywhere' (P13)
	Psychological aspects	'For a year ... I have experienced loss of concentration after taking ART medicine' (P8)
		'In the beginning I took medicine ... I experienced nausea, vomiting, I once thought ... why after taking medicine my appetite was reduced' (P5)

Social Support

Social support is the support obtained by participants in undergoing treatment. This theme was identified through sub-themes, namely: 1) family, and 2) peers. participants get support from the family in the form of instrumental support, which is accompanied by assistance in taking drugs every month; if the participants cannot take them themselves, the family helps monitor participants in terms of taking medicine and whether they have taken their medicine according to the dose and time. In terms of informational support, the family reminds them when to take the medicine. Another form of social support is the support of peers; their fellow PLWHA have an organization where they remember each other when taking drugs from each other.

Disease Management Skill

Disease management skills are the ability of individuals to be able to maintain a routine in order to remain well-implemented. In this study some participants already had good skills to manage medication times and to be on time, but there were also participants who had not been able to perform good skills, leading to carelessness in the consumption of ART. The identified sub-theme was the management of taking ART drugs. This covered t way or process of taking medication or obtaining medication carried out by participants. This sub-theme consisted of three categories: 1) efforts to minimize side effects, 2) efforts to obtain drugs, and 3) efforts to take medication according to the rules. One good effort made by HIV sufferers in minimizing side effects and timely taking of medication is shown below:

> *'I used to get dizzy when I woke up and it disturbed me to work, I used to drink at 9 pm but I advanced so at 7 pm so I didn't get dizzy when I woke up, now I rarely experience dizziness when I wake up' (P7)*
>
> *'I always use an alarm to help remind me to take medicine and carry medicine wherever I go' (P3)(P8)*

Adherence

This theme explains the participants' adherence to regular and timely medication and doses. Two sub-themes were identified namely: motivation and behavior. Motivation for adherence were obtained from personal, information provided by health workers, and motivation from family or friends with PLWHA. From personal obedience for fear of seeing the condition of other PLWHA who are not compliant experiencing opportunistic infections, and because of a loved family. Information from health workers also influences the adherence of HIV sufferers to take ART drugs; explanations from health workers related to the benefits and impacts of being compliant and not compliant in undergoing ART treatment are one of the reasons for participants' compliance in taking ART medication.

> *'Health workers said... that taking medicine regularly and must be on time. If they are not obedient, they will easily get the disease, then they will get opportunistic infections, so I will only obey, I don't want to add disease' (P4), (P11)*

Quality of Life

Quality of life in PLWH is usually associated with adherence with taking ART. This theme explains the perceptions of participants in terms of living their life. The sub-themes identified were in two categories, namely: 1) physical health aspects, and 2) psychological aspects. Aspects of physical health were in the form of physical activity. PLWHA usually already know the limits of their ability to carry out activities, and what are the impacts that will affect their activities. There was a psychological health affect from the aspect of physical health. The following statement came from the participants:

The authors in this study found six themes that emerged, namely: knowledge, self-motivation, social support, disease management, compliance and quality of life. The results of the assessment of researchers in the six themes show that there are themes that are interconnected and influence each other. The themes that were considered to be mutually influencing were: compliance and quality of life. The themes considered influencing him are self motivation, social support and disease management. Based on the experience of PLWHA, the theme affects the compliance and quality of life of PLWHA.

This study has also supported academic faculties and other researchers to continue to make appropriate and effective interventions to improve adherence and quality of life for PLWHA, as well as to identify the factors that influence them. This study is just a first step into studying and observing phenomena that occur and are experienced by PLWHA during antiretroviral therapy.

DISCUSSION

This study involved PLWHA with various backgrounds, ranging from contracting HIV/AIDS through needles to sexual relations (homosexual, heterosexual, bisexual) and from different economic backgrounds from middle to lower. The results of this study indicate that various experiences are experienced by PLWHA during their HIV care or when undergoing ART therapy. In several studies that have been carried out it has been stated that the reasons for non-compliance with ARVs are due to forgetfulness, careless use of ARVs and due to side effects (Sianturi, Perwitasari, Islam, & Taxis, 2019). In this study, besides being careless, forgetting and drug side effects, a reason for participants' non-compliance with ART was because they felt they were healthy, and they didn't feel any symptoms. Transportation was also a reason participants were not compliant in undergoing treatment. The unwillingness of participants to disclose their illnesses to families can also be a barrier in undergoing ART therapy, in PLWHA who have not revealed the status of the disease to family or friends; this can be an obstacle when they want to take medication, and they choose to delay taking medication.

Provision of misinformation about how to take ARV drugs and wrong perceptions of improving health can affect patients' compliance with ARV consumption (Mckinney, Modeste, Lee, Gleason, & Maynard-tucker, 2014).In this study, the reasons for non-compliance were found because of lack of clear information from health workers, or the fact that were not ready to receive information. Participants said they got a lot of HIV-related information from PLWHA companions. Alarms were considered an effective tool to remind them to take medicine on time. Previous research suggests that clocks and cellphones are seen as a contributing factor to help PLWHA remember to take medication on time (Neupane, Dhungana, & Ghimire, 2019). PLWHA who have good behavior skills have relevant information and sufficient motivation to make them compliant in taking ARV drugs (Horvath, Smolenski, & Amico, 2014). It needs to be clearly and repeatedly stated to people with HIV / AIDS (PLWH), that ART must be consumed for life and must be taken whether they are well or healthy, especially in those newly diagnosed with HIV.

Social support is very influential for improving quality of life especially for older and married people (Liu et al., 2015). Barriers to the quality of life of PLWHA lead to helplessness, where individuals are socially / emotionally hampered and lack support related to more severe symptoms due to HIV (Jesus1 et al., 2017). In participants who had their partners' support and reminded one another to take medication and in patients whose parents knew that they had HIV, they had the support to always take medication on time by being reminded when they have to take medication and scheduling for control. While those whose family did not know they had HIV received full support from their companions. Participants stated that the support they received from their family and companions was very meaningful to them and became their own motivation to remain adherent to ART therapy.

Research was conducted from November 2019 to January 2020 and found much non-compliance due to lack of knowledge, lack of disease management skills while undergoing ART therapy and impact on quality of life. There are studies that indicate that behavioral skills directly influence the adherence to taking ART drugs in PLHIV (Horvath et al., 2014).. It was also found that the problem most often experienced by PLWHA after taking ART was insomnia; participants complained of difficulty sleeping after they took the drug. HIV sufferers (Lindayani et al., 2018). Self-motivation and social support greatly influence the adherence to ART therapy and quality of life in PLWHA. More research needs to be done to increase knowledge, self-motivation or social and disease management behavior skills to be able to improve adherence and quality of life in PLWHA.

CONCLUSION

Knowledge or understanding of the disease and its treatment are considered to be very influential for patient adherence to ART treatment. Providing clear information and at the right time affects the receipt of information positively. Self motivation in the form of effects or benefits that are felt after consuming drugs and loved ones become the driving force for PLWHA to be routine and adhere to treatment. Social support for PLWHA is only obtained from those closest to them and their peers, because the patient's unpreparedness to disclose their status means only a few people know about the disease. Behavioral skills are needed to be able to maintain compliance and improve quality of life for the better. Compliance and quality of life are interrelated; if adherence to drugs is good, quality of life will be good too, but the most important factor of adherence or a good quality of life depends on behavioral skills in undergoing treatment. There is a need for a good understanding of behavioral skills to support compliance and a better quality of life.

CONFLICT OF INTEREST

No conflict of interest has been declared.

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